

**Coping with Stem Cell Transplant: An Interpretative  
Phenomenological Analysis of Patient Experience**

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## **Declaration**

This thesis has been composed by myself and the work contained is my own. It has not been submitted for the purpose of fulfilling any other degree requirements.

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‘The meaning of suffering: We must never forget that we may also find meaning in life even when confronted with a hopeless situation, when facing a fate that cannot be changed. For what then matters is to bear witness to the uniquely human potential at its best, which is to transform a personal tragedy into a triumph, to turn one’s predicament into a human achievement. When we are no longer able to change a situation – just think of an incurable disease such as an inoperable cancer – we are challenged to change ourselves.’ (Frankl, 1959/2004)



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## **ABSTRACT**

### **OBJECTIVE:**

The present study aimed to explore the subjective experience of Stem Cell and Bone Marrow Transplant recipients in relation to coping with the transplant process, comparing this experience with existing theoretical and empirical research relating to the psychological impact of transplant and coping with stress and cancer.

### **METHOD:**

A retrospective, cross-sectional qualitative design was used. Semi-structured interviews were conducted with six participants who had undergone transplantation in the period from January 2005 and December 2006. Individuals also completed measures of psychological adjustment (HADS, Zigmond & Snaith, 1983; MAC, Watson *et al.*, 1988) to provide an indicator of current emotional functioning. Participant's verbal accounts were transcribed verbatim and analysed according to the principles of Interpretative Phenomenological Analysis (IPA, Smith, 1996).

### **RESULTS:**

Seven shared themes were identified, six of which were of relevance to the research aim and analysed in further detail. These were: Existential Issues, psychological experience of the transplant procedure, physical side effects, relationships, change of meaning and altered perception of self and normality. Five out of the six participants completed both the HADS and the MAC, two participants scored above the clinical cut off point on the anxiety subscale of the HADS, suggesting borderline generalised anxiety. No participant scored above the clinical cut off point on the depression subscale of the HADS. No participant met clinical case criteria on the MAC.

### **CONCLUSION:**

The current findings were consistent with previous research and suggest that cognitive models of coping with stress and cancer may have conceptual utility in understanding the experience of coping with transplantation. Possible implications for future research, clinical practice and the participating service implications are identified and discussed.

## **1. LITERATURE REVIEW**

The following literature review aims to provide a context and rationale for the present study. Subdivided into three sections, the first section provides an overview of the process of Stem Cell and Bone Marrow Transplant, the physical side effects associated with this and the psychological impact of this procedure. The second section provides an overview of dominant conceptual models of stress and coping and outlines conceptual models of coping with cancer and Stem Cell Transplant. The final section provides an overview of the service in which the current study is undertaken and concludes with the research question and aims that the present study seeks to address.

### **1.1. Overview of Stem Cell and Bone Marrow Transplantation**

#### **1.1.1. Haematological Malignancy**

Haematological or blood malignancies are the fifth most common form of cancer in the UK (NICE, 2003). The umbrella term of haematological malignancy incorporates: Leukaemia, Lymphoma, Myeloma and associated subtypes. The forms of haematological malignancy vary in their severity, prognosis and treatment; however their underlying pathology is similar and principally involves an error in cell development and reproduction originating in the bone marrow.

Bone marrow, a tissue contained within our bones is responsible for the production of all blood cells; the cells which produce our blood cells are termed stem cells (Campbell, 2005). Stem cells are responsible for producing the 3 million red blood and 120 000 white blood cells we produce each second (Campbell, 2005). Red blood cells transport oxygen from the lungs to other cells within the body. White blood cells (of which there are multiple types) form part of the immune system and provide a defence mechanism against disease. In addition to the production of red and white blood cells, stem cells are able to reproduce themselves (Copelan, 2006).

If bone marrow fails as a consequence of disease and is no longer able to produce the cells required, the only treatments which can offer recipients a potential cure are Bone Marrow or Stem Cell Transplants. Otherwise recipients are likely to die from infection or uncontrollable

bleeding (Duncombe 2002). A single stem cell has the potential to restore haematological and lymphatic functions (Osawa *et al.*, 1996). See table 1 for details of conditions presently indicated for treatment with Stem Cell Transplant or Bone Marrow Transplant.

**Table 1. Conditions treated by Stem Cell or Bone Marrow Transplant**

<b>Allograft Transplant</b>
Primary Immunodeficiency Syndrome
Aplastic Anaemia
Thalassamaemia
Sickle Cell Disease
Inborn errors of metabolism
Chronic Myeloid Leukaemia
Myelodysplasia
Multiple Myeloma
Acute Myeloid Leukaemia
Acute Lymphoblastic Leukaemia
<b>Autograft Transplant</b>
Relapsed Non Hodgkins Lymphoma
Acute Myeloid Leukaemia
Multiple Myeloma
Relapsed Hodgkins Disease
Acute Lymphoblastic Leukaemia
Relapsed testicular Cancer
Chronic Myeloid Leukaemia
Severe Autoimmune Disease

(adapted from Duncombe, 2002)



### **1.1.2. Peripheral Stem Cell and Bone Marrow Transplant Procedure**

Stem Cell or Bone Marrow Transplantation is the term used to describe the complex treatment process used to treat bone marrow failure as a consequence of haematological malignancy or otherwise incurable inherited genetic conditions (Campbell, 2005; Kolb, 2006). Following the first successful treatment of haematological malignancy by bone marrow transplant in the 1950's (Thomas *et al.*, 1957), transplants have become an increasingly common place treatment (Duncombe, 2002). Between 1990 and 2005, 29605 transplants were undertaken in the United Kingdom, with 2578 first transplants recorded in 2005 (British Society of Blood and Marrow Transplantations, 2007)

Haematological cancers occur when normal stem cells produce malignant stem cells which then reproduce themselves (Bonnet & Dick, 1997). Transplantation involves the destruction through either radiotherapy and or chemotherapy of existing bone marrow and hopefully malignant stem cells. This is followed by re-introduction of stem cells or bone marrow with the hope that bone marrow will regenerate and restore haematological and immune function (Duncombe, 2002).

Originally bone marrow was directly removed from bones through needle aspiration; however it is now possible to remove peripheral stem cells directly from patient or donor blood through a stem cell separator. Stem cells or bone marrow tissue are harvested prior to hospital admission for transplantation and cryogenically frozen, enabling them to be stored for long periods of time without damage to cells occurring. On completion of chemo or radiotherapy bone marrow or peripheral stem cells are defrosted and transfused back to the patient (Duncombe, 2002).

When bone marrow is directly transfused this is known as a Bone Marrow Transplant (BMT), when peripheral stem cells are used this is known as a Peripheral Blood Stem Cell transplant or more commonly abbreviated to Stem Cell Transplant (SCT). Stem cells or bone marrow can be harvested from either the individual undergoing transplant (autograft) or from a tissue matched donor (allograft). Allograft donors are typically siblings or unrelated individuals whose tissue type is matched to the patient.



The process of radiotherapy and or intensive chemotherapy which recipients undergo with the purpose of eradicating their disease is known as conditioning. The purpose of conditioning is to cause cell death. As haematological malignancy is related to faults in haematological cell reproduction, the destruction of cell tissue is intended to eradicate these errors. However, destruction of cells would result in death if there were no process by which to re-establish cell generation. Consequently, following conditioning, harvested cells are returned to the individual to facilitate cell regeneration and consequently 'rescue' them.

It is possible for some malignant stem cells to survive treatment or in the case of autograft transplants, contaminate the cell harvest resulting in recurrence of disease. (Brenner *et al.*, 1993; Copelan, 2006;). Therefore, although transplantation is utilised as a potentially curative treatment, its success is not guaranteed. SCT result in higher levels of cure and remission than alternative chemotherapy regimens but this comes at a cost in terms of higher levels of treatment-related mortality and morbidity (Copelan, 2006). Transplantation is associated with levels of mortality resulting from treatment complications, ranging from 3 – 50% dependant on diagnosis and transplant type (Loberiza *et al.*, 2005). The first year post-transplant is the most risky, with levels of treatment related mortality of 5-15% for autograft recipients and 20-50% for allograft recipients (Loberiza *et al.*, 2005).

Given the risks involved in transplant, recipients are rigorously assessed before being considered for transplantation and may be not be offered this option or have the possibility of transplant withdrawn if their general health or other conditions mean they are less likely to survive the transplant process (Campbell, 2005). Furthermore, due to the risks involved there is an upper age limit for both processes, around 55 for allograft transplants and 70 for autograft (Duncombe, 2002).

### **1.1.3. Physical Side Effects**

Side effects can be nominally divided into those occurring in the short term, generally immediately following transplantation and delayed effects occurring in the longer term.

#### **Acute Physical Side Effects**

Completion of transplantation is followed by a period in which bone marrow and stem cells are regenerating (up to 4 weeks), during which there is a risk of life threatening

complications e.g. infection or bleeding. This period of time is spent being nursed in isolation (Anderson *et al.*, 2001). Additional side effects include mucositis (inflammation of mouth and intestinal mucus membranes) which causes severe pain; nausea; diarrhoea and cramping (Copelan, 2006), and venal occlusive disease which can result in liver, kidney and respiratory failure (DeLeve *et al.*, 2002). Transplant related lung damage is associated with mortality levels of up to 60% (Copelan, 2006). Cytomegalovirus pneumonia (CMV) a viral infection remains dormant following infection and may be reactivated by transplantation.

An additional acute risk of Allograft transplantation is graft versus host disease (GVHD) in which the cells transplanted from a matched donor attack those of the recipient (Alby, 1991). Acute GVHD results in damage to skin, digestive tract, liver and lowered immune response, predisposing recipients to infection. All recipients receiving allograft transplants are potentially at risk of acute GVHD which ranges from mild to life threatening and develops within the first three months following transplant (Sullivan *et al.*, 1986).

### **Long-term Physical Side Effects**

In addition to the acute side effects, stem cell and bone marrow recipients are at risk of developing chronic problems or delayed side effects of treatment. Chronic GVHD, which can develop from 3 months post-transplant, varies in intensity from mild to severe. Levels of chronic GVHD range from 20 - 70% and the condition is associated with higher levels of mortality unrelated to disease relapse (Flowers *et al.*, 2002; Lee, 2005). Multiple organ involvement occurs in 50 % of cases (Lee, 2005).

Further long-term complications include cataract formation (Deeg *et al.*, 1984), problems with iron metabolism (McKay *et al.*, 1996), osteoporosis (Schimmer *et al.*, 2000) and necrosis of bone tissue (Socie *et al.*, 2003). Liver function may also be impaired (Socie *et al.*, 2003). Lung damage related to transplant occurs in up to 20% of allograft survivors (Socie *et al.*, 2003) in particular restrictive lung disease and chronic obstructive airways disease. Recipients may recover from restrictive lung disease; however chronic obstructive airways disease is generally irreversible.

Transplantation severely impairs fertility in adult patients, with male recipients being unable produce sperm and female recipients unable to ovulate (Copelan, 2006; Socie *et al.*, 2003).

Due to cessation of hormone production women are at increased risk of osteoporosis (Socie *et al.*, 2003).

Secondary malignancy may also occur post-transplantation. Allograft transplantation increases the risk of skin, oral, central nervous system, thyroid and bone cancer (Copelan, 2006) and lymphoproliferative disorders (Deeg & Socie, 1998). Overall the incidence of secondary malignancy is low (Deeg & Socie, 1998), but certain groups may be at high risk, in particular those with chronic GVHD (Socie *et al.*, 2003; Socie, 2006). Following Autograft transplant for lymphoma, an increased risk of myelodysplasia and acute leukaemia has been noted (Copelan, 2006)

In addition to research outlining the physical consequences of SCT and BMT, an increasing body of literature relating to the psychological impact of the procedure has developed. Before proceeding to discuss theoretical conceptualisations of stress, coping and the relationship between these and psychological adjustment the literature pertaining to psychological aspects of stem cell and bone marrow transplants will be discussed.

#### **1.1.4. Psychological Impact of Stem Cell and Bone Marrow Transplant**

Transplantation has been demonstrated to impact on all those involved including medical staff, families and carers of transplant recipients (Andrykowski & McQuellon, 1999). However, the specific focus of the present study is limited to the psychological experience of adult transplant recipients. Research investigating psychological impact tends not to make the distinction between SCT and BMT. The following provides a brief overview of this literature.

#### **Prevalence and Nature of Psychological Distress**

The term psychological distress in research relating to this population generally refers to clinically significant levels of anxiety and depression. Pre-transplant levels of anxiety and depression have been linked to poorer psychological and physical functioning post-transplant and higher levels of mortality. High levels of depression and anxiety occur during hospital admission for the procedure; these are associated with a range of factors including isolation and physical side effects.

Up to 44% of recipients report clinically significant levels of depression or anxiety prior to transplantation (Grassi, 1996; Preito *et al.*, 2002), levels which may persist throughout the recovery phase post-transplant (Lee *et al.*, 2005; Neitzert *et al.*, 1998). These levels of adjustment difficulty are significantly higher than other cancer patients (Anderson *et al.*, 2001). High levels of distress pre-transplant are relevant to both autograft and allograft transplant. Research has suggested that allograft recipients experience higher levels of anxiety and depression than autograft recipients (Neitzert *et al.*, 1998). However this conclusion is controversial as other studies have found no difference between transplant types (Leigh *et al.*, 1995).

The point at which greatest psychological distress occurs is the period after admission to hospital but prior to transplantation (Fife *et al.*, 2000). The lowest recorded levels of distress occur at 3 and 12 months post-transplant. Baseline levels of distress are associated with post-transplant distress; with those reporting higher levels of distress pre-transplant continuing to demonstrate higher levels 12 months post-transplant (Fife *et al.*, 2000; Lee *et al.*, 2005).

Few studies have specifically examined factors associated with distress prior to transplant. However one study suggests that perception of personal control is associated with lower levels of distress. Those who perceive a greater sense of control over their life pre-transplant experience significantly lower levels anxiety and depression both pre and post-transplant than those who perceived a lack of control over their life (Fife *et al.*, 2000). High levels of pre-transplant distress, in particular depression are associated with poorer post-transplantation adjustment, physical recovery and higher mortality (Lee *et al.*, 2005, Molassiotis, 1997; Pearman, 1998, Loberiza *et al.*, 2002). The mechanisms by which this influence occurs are unclear but may be related to poorer self care and reduced compliance with complex medication regimes. However, there is a lack of research examining compliance to medication post-transplantation in this population (Bishop *et al.*, 2002).

In addition to pre-transplant distress, factors identified with anxiety and depression during admission for the transplant procedure include being nursed in isolation; uncertainty regarding the future; age; distance from home and physical side effects. Distressing side effects include nausea and vomiting, problems with appetite; bowel function; insomnia and fatigue (Anderson *et al.*, 2001; Futterman *et al.*, 1991; Leigh *et al.*, 1995, Molassiotis *et al.*, 1996). Distress associated with physical symptoms is correlated with clinically significant

levels of depression and anxiety across the transplant process. However, the relationship between physical side effects and psychological distress is complex with studies suggesting that clinical anxiety and depression prior to transplant predict increased perception of pain during the procedure and a longer duration of stay in hospital (Prieto *et al.*, 2002; Schulz-Kindermann *et al.*, 2002). Post-transplant, increased activity levels are correlated with reduced symptom distress (Molassiotis *et al.*, 1996; Neitzert *et al.*, 1998).

Research has tended to limit exploration of the psychological impact of SCT to anxiety and depression, one study has been published which examines the relationship between Post Traumatic Stress Disorder (PTSD) and transplant (Widows *et al.*, 2000). Five percent of participants met the criteria for a formal diagnosis of PTSD, with high levels of traumatic symptoms reported by the entire sample (an average of 3-4 symptoms). Traumatization was associated with the experience of the transplant procedure not other traumatic events.

### **Long-term Psychological Impact**

A number of papers have been published in recent years which aim to look at the long-term psychological impact of stem cell and bone marrow transplant (Andrykowski *et al.*, 2005; Byar *et al.*, 2005; Fife *et al.*, 2000; Gruber *et al.*, 2003; Hjermstad *et al.*, 2004). These studies suggest that even following successful transplantation, survivors may experience long-term problems with psychological adjustment and may not return to full physical health.

A large scale long-term follow up of transplant survivors (N=662, mean 7 years post-transplant) examined health related quality of life and well being compared to a matched sample of healthy individuals (Andrykowski *et al.*, 2005). The results indicate that years following transplant, survivors demonstrate poorer perceived health, physical functioning and psychological adjustment compared to the control group. Transplant recipients described an expectation that life would return to normal following transplantation and that the reality was often not the case. Andrykowski *et al.* (2005) conclude that violation of this expectation may be the precipitant to poorer psychological adjustment, with ongoing physical problems and risk of recurrence being possible maintaining factors for poorer psychological adjustment.

Other research suggests that the higher the level of symptomatology at 12 months post-transplant the higher the level of distress (Fife *et al.*, 2000). Similar to Andrykowski *et al.*



(2005), Fife *et al.* (2000) conclude that a reduction in psychological distress immediately post-transplant, can be attributed to recipients perceived 'hope for future' and belief that they will return to normal functioning. Those who experience significant long-term physical problems must come to terms with the prospect that they will never attain functioning comparable to that they experienced prior to their illness and treatment.

In addition to the negative psychological impact of transplant, those who are successfully treated may experience positive psychological consequences (Andrykowski *et al.*, 2005). Transplant survivors' demonstrated increased perceptions of spiritual and psychological growth compared to healthy controls. Whilst the inclusion of a large number of measures (n=24), may have inflated the possibility of achieving significant results; overall the study is useful in highlighting the potential for positive psychological outcome of the transplant process.

The evidence so far suggests that SCT is a medical procedure associated with high levels of psychological distress, in particular anxiety, depression and PTSD. Loss of perceived control, physical side effects and violations in the belief that transplantation will return recipients to normality are associated with distress. The research base is limited and largely descriptive, nevertheless findings are generally consistent. This is not however the whole picture, with one study suggesting that transplant survivors may also experience positive psychological growth and enhanced meaning post-transplant. In addition to the empirical research outlined, a small number of qualitative studies have been undertaken with this population. Consideration of these adds to our understanding of the psychological experience and impact of SCT.

### **Qualitative Research Relating to the Psychological Impact of Transplantation**

A handful of studies exploring the experience of transplant recipients have been identified (Ferrell *et al.*, 1992; Holmes *et al.*, 1997; McGrath & Montgomery, 2006; Xuereb & Dunlop, 2003). Qualitative methods used include grounded theory, interpretative phenomenological analysis and content analysis of interview material. Predominantly these studies focus on meaning and quality of life post-transplant among those undergoing SCT/BMT. No studies have been identified exploring specifically the psychological impact of transplantation; however themes of relevance can be identified from these studies.

Conducting a phenomenological analysis of accounts from transplant survivors (n=119), Ferrell *et al.* (1992) explore the conceptualisation of quality of life (QOL) with transplant survivors. Themes identified by participants as signifying quality of life included: being independent, being healthy, being able to work, having family relationships, having a heightened appreciation for life, being alive, being satisfied and fulfilled with life and being normal. Transplant was viewed to have impacted on QOL in both positive and negative ways. The positive effects of transplantation were providing a second chance, the opportunity to improve quality of life and increased spirituality and appreciation of life. Ongoing physical side effects, reduced strength and stamina and restricted activities were perceived as the negative effects of BMT on quality of life. Psychological well being post-transplant was influenced by emotional distress such as anxiety and depression, fear of disease recurrence, desire for normality and an increased appreciation for life.

A similar study conducted by Holmes *et al.* (1997) identified themes of physical health, ability to work, appreciation of life, social wellbeing, family and friendships as supportive, and being normal as pertinent to QOL. Transplant was associated with physical, social and psychological problems, with participants experiencing difficulties in re-establishing normality post-transplant. The majority of participants felt however that they had a quality of life which was similar to or improved from their pre-transplant quality of life. The authors conclude that perceptions of retained or improved quality of life (in spite of ongoing problems) were associated with the altered sense of self and enhanced meaning experienced by participants. As the following quote exemplifies:

‘Having faced a life threatening illness, most participants stated that they were leading fuller, more meaningful lives and had developed a greater appreciation for life’ ( Holmes *et al.*, 1997, p109)

A conclusion supported by Xuereb and Dunlop (2003), who also found that meaning is integral to the experience of transplantation with the experience impacting on the whole person. They suggest that the experience of transplantation:

‘brought many of the participants to reappraise their lives, to be less concerned with material goals, and to strengthen relationships with others. The ways in which people make meaning and find agency in the process of living vary according to their personal goals and values’ (Xuereb and Dunlop, 2003, p406).

To summarise, qualitative studies exploring the impact of transplantation on QOL, identify that psychological wellbeing is an inherent aspect of quality of life and that emotional distress, desire for normality and alterations to participants perceived meaning of self and life in general are themes pertinent to psychological wellbeing. Transplantation is not conceived of as a procedure occurring in isolation from the individual but is viewed as impacting on the whole self. As with empirical studies, the psychological impact of transplant is not viewed as entirely negative.

### **1.1.5 Summary of Section**

Section one has outlined the procedure of SCT and BMT, the side effects associated with this and provided an overview of the psychological impact of transplantation. Transplantation is a life threatening medical procedure which has a global impact on physical and psychological functioning of recipients. The evidence considered so far indicates a complex and ongoing relationship between psychological distress and physical side effects of the transplant procedure. For a large proportion of recipients physical side effects are enduring and have a continuing impact on functioning, even in the absence of the disease for which they underwent the transplant. For some however, transplantation can offer the potential for new positive meaning and improved quality of life.

There is a lack of a conceptual base providing a systematic understanding of the processes underpinning coping with SCT and BMT. Transplantation does not universally result in problems with psychological adjustment, therefore understanding factors relevant to coping with transplantation could have potentially important clinical implications for assisting those undergoing this procedure. Both forms of transplant are life threatening treatment for life threatening disease, what this points to is a conceptualisation of the procedure as an acute stressor occurring within the context of a chronic stressor. Consequently for the purpose of the present study, an overview of theoretical perspectives on coping and psychological adjustment to stress will be provided.

## **1.2. Coping and Psychological Adjustment to Stress**

Following an overview of theoretical perspectives on stress and coping, an outline will be provided of psychological adjustment to cancer in general and a cognitive model of coping



and psychological adjustment to cancer. Finally, the limited research which specifically relates to coping with SCT will be reviewed.

### **1.2.1. Stress**

The terms stress and coping are used widely, however a definition is often more difficult to achieve (Lazarus, 1999). Dougall and Baum (2001) suggest that certain broad assumptions underlie all theoretical positions on stress. Principally that stress is an adaptive response, related to threat and associated with the experience of unpleasant emotional and physiological responses. The following section will provide a brief outline of the main models of stress, from biological to more explicitly psychological. A broad array of models exists pertaining to varying conceptualisations and consequent methods of measurement of stress. It is beyond the scope of the present study to provide a complete review of these perspectives.

### **1.2.2. Biological Models of Stress**

The earliest models of stress relates to the work of Cannon (1914) and Seyle (1936/1956). Both Cannon and Seyle suggest that stress is a physiological response to an external stimulus which poses a threat. Neither specifies what constitutes a stressor or the mechanisms by which we perceive events or objects as stressors. Seyle acknowledged the potential for psychological threats to activate the stress response but did not indicate how an indirect threat activates the same response as a direct physiological threat. Due to the limited explanatory value of physiological models of stress, psychological models positing an increasing role for psychological factors in explaining stress have gained dominance.

### **1.2.3. Psychological Models of Stress**

Psychological models have tended either to propose that stress may best be explained in stimulus-response terms with an external event or object, known as a 'stressor', acting on the individual (the impact of the stressor being stress). Or alternatively have proposed that stress is a process experienced by the individual, dependent on an interaction between an event and the individual, mediated through the individual's perception of the impact of the stressor.

Before proceeding to discuss interactional models of stress, brief consideration will be given to a stimulus-response model of stress which envisages the potential for threat as located in an external stimulus such as a life event. That is a stressor is an environmental stimuli which causes physical or psychological distress in the individual experiencing it.

### **Life Events as Stressors**

Theoretical perspectives attributing problems with psychological adjustment to external events can be traced back to the early work of Holmes and Rahe (1967). Such perspectives suggest that external events may cause the development of psychological problems. These models regard stress as a stimulus-response process.

Looking to explore a possible connection between stress and ill health, Rahe *et al.* (1964) examined the medical records of individuals who had recently suffered illness. They asked these individuals to indicate what life events they had recently undergone; many had experienced major life events prior to illness. This association led to the proposition that adaptation to a stressor may leave individuals vulnerable to future illness. Based on this work, Holmes and Rahe (1967) proposed a model of stress whereupon life events which require adaptation by the individual result in stress. The precipitating event need not be negative but may be any event which requires adaptation. Their principle argument being that the stress associated with life events may be cumulative and the greater the number of events experienced by an individual, the greater the total amount of adjustment and ultimately the greater the level of stress experienced.

However, as with biological models, the life event as stressor model has limited explanatory value. For instance, it does not explain why individuals do not experience the same events as stressful or experience stress to the same degree. This leads to the theory that it is the appraisal of an event as being negative or stressful which determines the experience of the event as being stressful.

## **Cognitive Mediation of Stress**

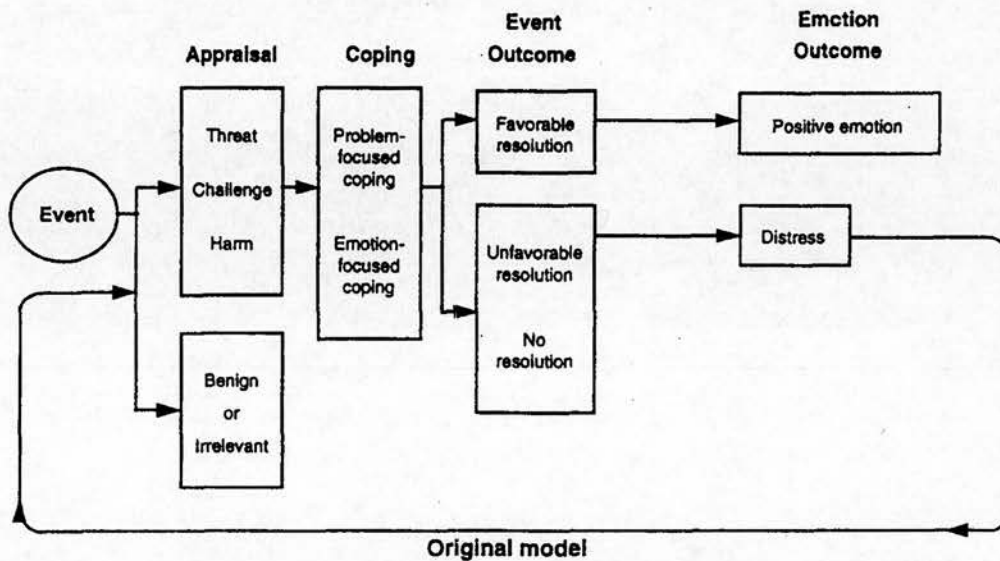
The cognitive mediation of stress was initially proposed by Lazarus in 1966 (Lazarus, 1966). Later expanded by Lazarus and Folkman (1984) this theory suggests that stress is not something which happens to an individual passively, it requires the individual to perceive and respond to stimuli within the environment. Thus stress is a transaction between the individual and their environment.

Lazarus and Folkman (1984) defined stress as:

‘a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well being’. (p19).

Underpinning Lazarus and Folkman's model (1984) is the idea that it is not the inherent qualities of the stimulus per se which leads to a stress response but rather the individual's appraisal of the threat posed to them by the situation. Stress occurs when there is an imbalance between the perceived demand on the person and their perceived resources for dealing with it. Stress and distress will not occur if an event is perceived as non-threatening or if the individual perceives that they have sufficient resources to cope with any potential threat. Distress or negative affect is experienced if an event is appraised as threatening and the individual perceives that they do not possess sufficient resources to cope or initial attempts at coping fail to reduce the perception of threat. Figure 1 shows a diagrammatic representation of model.

The process of coping and psychological adjustment to stress is dependent on two levels of appraisal: Primary appraisal – this is an initial evaluation as to whether an event or object is a threat; Secondary appraisal – an appraisal of whether sufficient resources are available to cope with the threat. Primary and secondary appraisals constitute the extent to which an event is considered to be threatening or challenging and the level of control that an individual perceives they may exert over the stressor.



**Figure 1: Diagrammatic Representation of Cognitive Mediational Model of Stress (Lazarus and Folkman, 1984)**

(Folkman 1997, figure 5, p1217)

The concept of coping is inherent in Lazarus and Folkman's (1984) model, if an event is appraised as stressful, coping responses are utilised in an attempt to reduce the negative impact of the stressor. Coping relates to the thoughts and behaviours an individual uses to manage the event, object or situation. Coping strategies take two forms, those aimed at reducing and regulating distress are termed emotion focussed coping, those used to manage the stressor are termed problem focussed coping. Should coping result in favourable resolution and amelioration of distress, cessation of the stress response occurs. If however no successful resolution occurs and distress remains, further appraisal will occur and the process continues.

Lazarus (1999) acknowledges that there is similarity inherent in particular events which are more likely to be appraised as threatening, i.e. bereavement or serious illness. Situations which are highly familiar are predictable and have clear boundaries favoured an appraisal of challenge. Those which are imminent, novel, unpredictable, ambiguous, take place in the face of a number of other stressors and which are of chronic duration are likely to be

appraised as threatening. Although it is more likely that a situation will be perceived as threatening, it is still a transaction between this situation and the personal characteristics of the individual involved. Thus individuals will interpret the meaning of a situation in different ways and the meaning afforded to the situation will determine their level of psychological distress.

#### **1.2.4. Summary**

Stress can be conceptualised as a physiological response to an external stimulus, a response to events requiring adaptation or as an interaction between an individual and their environment mediated by cognitive appraisal. Each theoretical conceptualisation emphasises different aspects of the process, yet underlying all is a shared assumption. Namely that stress and coping is a process which occurs as an interaction between an individual and their environment. However, it could be argued that Lazarus and Folkman's (1984) model provides the most comprehensive and widely accepted explanatory model of the psychological processes underlying coping and psychological adjustment to stress.

#### **1.2.5 Coping**

Coping, like stress is a theoretical concept which is hard to define, yet widely investigated (Folkman & Moskowitz, 2004). Definitions of coping and what constitutes coping behaviour are multitudinal; however throughout all research appears to be a basic underlying assumption that coping is the process by which an individual attempts to mediate the impact of a stressor (Stanton *et al.*, 2001). That is the idea that there is something to be coped with, for that reason models of coping are intrinsically linked to models of stress.

The following provides a brief overview of the origins of the concept of coping in the psychodynamic concept of defence and the more recent cognitive mediational theories based on Lazarus and Folkman (1984). The concept of coping is not these conceptualisations, however these have dominated the field of coping research (Folkman & Moskowitz, 2004). Folkman and Moskowitz (2004) suggest the following definition:

'coping is a complex, multidimensional process that is sensitive to both the environment, and its demand and resources[...]coping is strongly associated with the regulation of emotion, especially distress, throughout the stress process.' (p747)



### **1.2.6. Coping as Defence**

Historically conceptualisation of coping can be traced back to the psychodynamic concepts of ego defence first suggested by Freud. In his seminal paper, the Neurosis of Defence, Freud (1894/ 1989) formulated defence as a mechanism by which painful or distressing information is distorted or repressed thereby preventing conscious experience. Defences are processes operating outside conscious awareness and are used by the individual to deal with a perceived threat (Somerfield & McCrae, 2000; Cramer, 2000).

Psychodynamic formulations of defence dominated conceptualisation of coping until the shift in the late 1960's and 1970's, when Lazarus's early work suggested that coping was not merely an unconscious defence aimed at ameliorating anxiety originating from psychic conflict, but incorporated the active cognitive and behavioural strategies individuals utilise to reduce distress and alter the circumstances producing their distress (Lazarus, 1966). It is at this point that the idea of coping as a distinct phenomenon emerges (Folkman & Moskowitz, 2004).

This conceptualisation differs from the dynamic formulation in that the individual is perceived of as being consciously aware of their distress and the cause of this and as having the capacity to intentionally act on the environment to reduce this impact.

### **1.2.7. Cognitive Mediational Model of Coping**

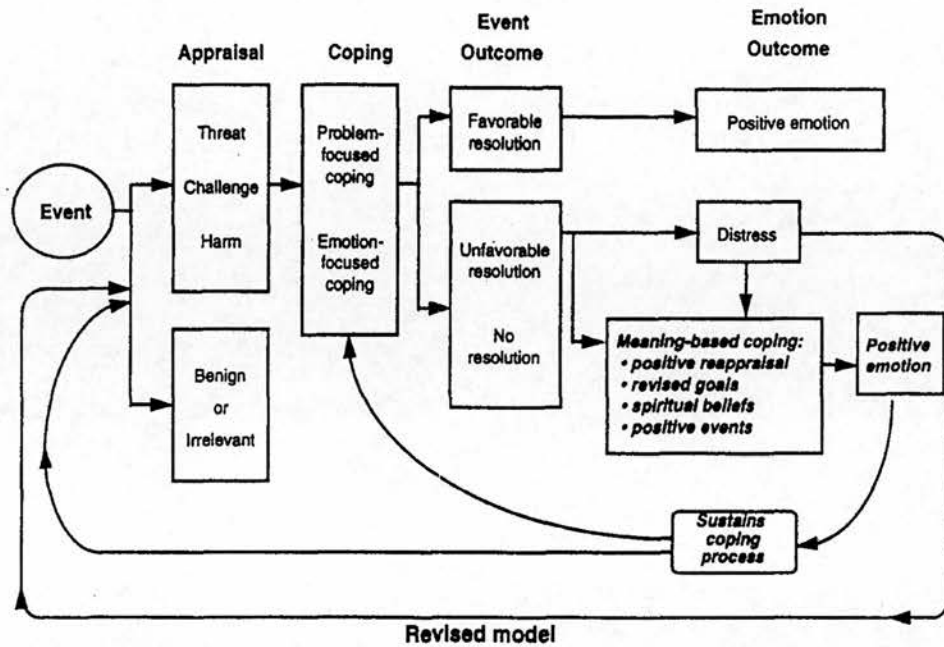
Coping within cognitive mediational models refers to a broad range of strategies utilised to minimise the impact of a stressor within a particular context. It describes a process which can be active or passive, cognitive or behavioural and conscious or unconscious (Lazarus & Folkman, 1984). Coping is initiated when a situation (stressor) is appraised as a potential threat, loss or harm to the individual and or their goals.

Coping strategies reduce the negative emotional impact of the stressor (emotion focussed coping) or to alter the stressor to reduce its potential negative impact (problem focussed coping). Attempts at coping will lead to either favourable resolution resulting in positive emotional outcomes and cessation of coping process or unfavourable resolution or no resolution which results in distress and continuing attempts to manage this through coping.

Research indicates that situations in which the individual perceives that they have a higher level of control are associated with problem focused coping strategies, such as information seeking, problem solving and direct action. Situations in which the individual has limited control are associated with increased use of emotion focused strategies, these include escape, avoidance, social support, distancing and cognitive reframing (Folkman & Greer, 2000). Undoubtedly personality characteristics and experiences are likely to shape the appraisals that individuals make (Folkman & Greer, 2000), however it is beyond the scope of the present review to cover this research.

Based on empirical research exploring the experiences of caregivers of men dying from AIDS, Folkman (1997) revised Lazarus and Folkman's original model (1984). Consistent with the earlier model, Folkman proposes that the processes of appraisal and coping underlie the experience of stress and subsequent ability to cope with this experience. However, coping mechanisms should be adapted to incorporate meaning based coping strategies which result in positive emotional experience. Coping is revised to incorporate 3 distinct categories of responses: emotion focussed coping consisting of the thoughts and behaviours utilised to regulate distress; problem focussed coping consisting of strategies used to manage the problem initiating the response; and finally, meaning based coping which is constituted by attempts to maintain positive well being by re-evaluating life goals to accommodate changes enforced by the problem. Figure 2 shows Folkman's (1997) revised model.

Meaning based coping is initiated when initial coping efforts result in an unsatisfactory resolution. Incorporating strategies including positive reappraisal of the meaning of the situation; revision of goals in light of present circumstances; altered meaning through spiritual beliefs and finally focussing attention on positive events or meaning in the present situation, meaning based coping functions as an alternative pathway to positive emotion sustaining the coping process. The interesting implication of this is that positive and negative affect may co-exist in the context of an unresolved stressor.



**Figure 2: Diagrammatic Representation of Revised Cognitive Mediation Model of Coping With Stress (Folkman , 1997)**

Folkman (1997, Figure 5, P1217)

### 1.2.8. Meaning and Coping

The concept of meaning is inherent to Folkman's (1997) cognitive model of coping. Park and Folkman (1997) make further distinction between global meaning and situational meaning. Global meaning is the most abstract form of meaning and describes a general orientation to life, incorporating fundamental assumptions, beliefs and expectations about the self i.e. perceived control and value of self, the world and purpose in life. Shaped by past experiences global meaning influences appraisal of the present and expectation of the future. Situational meaning refers to the interaction between global meaning and the situation or context within which an individual is embedded. Situational meaning in relation to stress and coping refers to the transactional process and resultant outcome, akin to the meaning based coping strategies proposed by Folkman (1997).

Reappraisal of situational meaning may alter global meaning, this process typically occurs when other coping efforts are unsuccessful or the stressor is severe and uncontrollable. Changes in global meaning i.e. alteration of beliefs and expectations about the world may



further alter appraisal of the stressor. Changes to global meaning can be perceived as positive and representing psychological or spiritual growth, or negative resulting in a perceived disintegration of the self or loss of meaning resulting in psychopathology such as PTSD (Janoff-Bullman, 1992).

Although this review has predominantly discussed cognitive models of coping and meaning, other perspectives on understanding psychological experience have long considered these issues. For example, existential perspectives have emphasised consciousness and our reflexive awareness as key to understanding our experience and actions (Stevens, 1996). It is self-awareness and capacity to act on this awareness which is intrinsic to our experience of life, for instance, we are aware of our own emotional experience, our actions, we can imagine our future self and we are aware of our finiteness. This enables us to reflect on the meaningfulness of our lives and to act on the meaning we perceive. This is somewhat similar to what Park and Folkman (1997) term global meaning.

Consideration of such existential issues is apparent throughout the history of philosophy, art and psychology (Stevens, 1996), and more recently existential psychotherapists such as Frankl (1959/2004) and Yalom (1980). Both Frankl (1959/2004) and Yalom (1980) consider the creation of meaning and awareness of finiteness as being inherent to the experience of living. In particular, Yalom (1980) proposes that life and death exist simultaneously; the fear of death shapes our experience of life. We all live with the knowledge that we will die, it is ever present. Yet this can be a positive enriching aspect of our experience of life. Our very awareness of our mortality enables us to live, to act in the knowledge that our time is limited.

‘although the physicality of death destroys man, the idea of death saves him’  
(Yalom, 1980, p30)

### **1.2.9. Summary**

To summarise, underlying the differing theoretical models of coping are a set of shared assumptions, namely that coping first and foremost requires the perception of threat and that this perception results in a response, either cognitive or behavioural to alleviate the impact of this threat. That is, coping is an active process involving the response to an appraisal through either activation of routine or novel responses; this can be a conscious or unconscious process.

Recent models and theoretical discussion regarding the nature of coping suggest that in addition to coping strategies which focus on reducing emotional distress and those which seek to change the stressor, the category of meaning based coping should be incorporated in conceptualisation of the coping process (Folkman, 1997; Park & Folkman, 1997).

### **1.2.10. Social Support**

Distinct from cognitive appraisal models of coping is the concept of social support as a positive influence on coping with stress. Whilst this idea is broadly accepted, definitions are multiple and often lack relevance to the context to which they are applied (Williams *et al.*, 2004). A broad definition suggests that social support is the:

‘resources and interactions provided by others that may be useful for helping a person to cope with a problem’ (Ashby-Wills & Filer-Fegan, 2001, p209)

Williams *et al.* (2004) suggest that the distinction between models of social support relate to whether it is a continuous process enhancing wellbeing or whether it specifically occurs in response to stress. Evidence favouring one or the other model is equivocal (Ashby-Wills & Filer-Fegan, 2001). Cassel (1976) proposes that social support buffers the individual from potentially adverse physical and psychological consequences of a stressor and thereby facilitates coping. Social support intervenes between the stressor and the individual and occurs like the concept of coping in the context of a stressor. In contrast, Thoits (1982) suggests that social support is an ongoing process occurring unrelated to the stress response which directly impacts on wellbeing.

Nevertheless evidence suggests that social support, in particular emotional support, may be beneficial to health on a wide range of outcomes both physical and psychological (Ashby-Wills & Filer-Fegan, 2001; Stanton *et al.*, 2001). For example high levels of social support are associated with significantly reduced levels of mortality following cardiac surgery (Williams *et al.*, 1992). Increasingly however, research has indicated that social relationships may also have a negative impact on psychological adjustment and that the value of social support is dependent on individual appraisal and meaning of the support provided (Stanton *et al.*, 2001).

### **1.2.11. Coping and Psychological Adjustment to Cancer and SCT**

Cancer is a common condition which accounts for approximately 25% of deaths (Barracough, 2000). The term cancer is perhaps best understood as describing the underlying physiological process of dysfunction in cell division and reproduction (leading to overproduction of cells) rather than as single diagnostic term. Cancer may affect any aspect of the body; however cancers vary in the prognosis and treatment, although all pose a potential threat to life without treatment. Of those diagnosed with cancer, treatment will eradicate disease in around 33% of cases; again this is dependent on the cancer type and the stage at which diagnosis occurs (Barracough, 2000). Due to improved treatment regimes leading to increasing survival rates, cancer is conceptualised as a chronic illness (White, 2001).

### **1.2.12. Psychological Impact of Cancer**

Given the threat to survival inherent in a diagnosis of cancer, diagnosis is almost universally appraised as a threat resulting in activation of the stress and coping process. A period of psychological distress termed an adjustment reaction is regarded as normal (White, 2001). Typical responses include: shock, fear and anxiety, sadness and despair, anger, guilt and shame, relief, sense of challenge and acceptance (Barracough, 2000). Psychological distress may persist or occur at other points in the disease trajectory, resulting in impaired functioning and clinically significant levels of anxiety and depression (White, 2001).

Clinically significant levels of psychological distress vary dependent on cancer site, however on average 20% of cancer patients will meet the diagnostic criteria for a formal psychiatric disorder (Barracough, 2000; White, 2001). A further 30% of cancer patients are classified as having an adjustment reaction to their illness, demonstrating psychological distress at a sub clinical threshold.

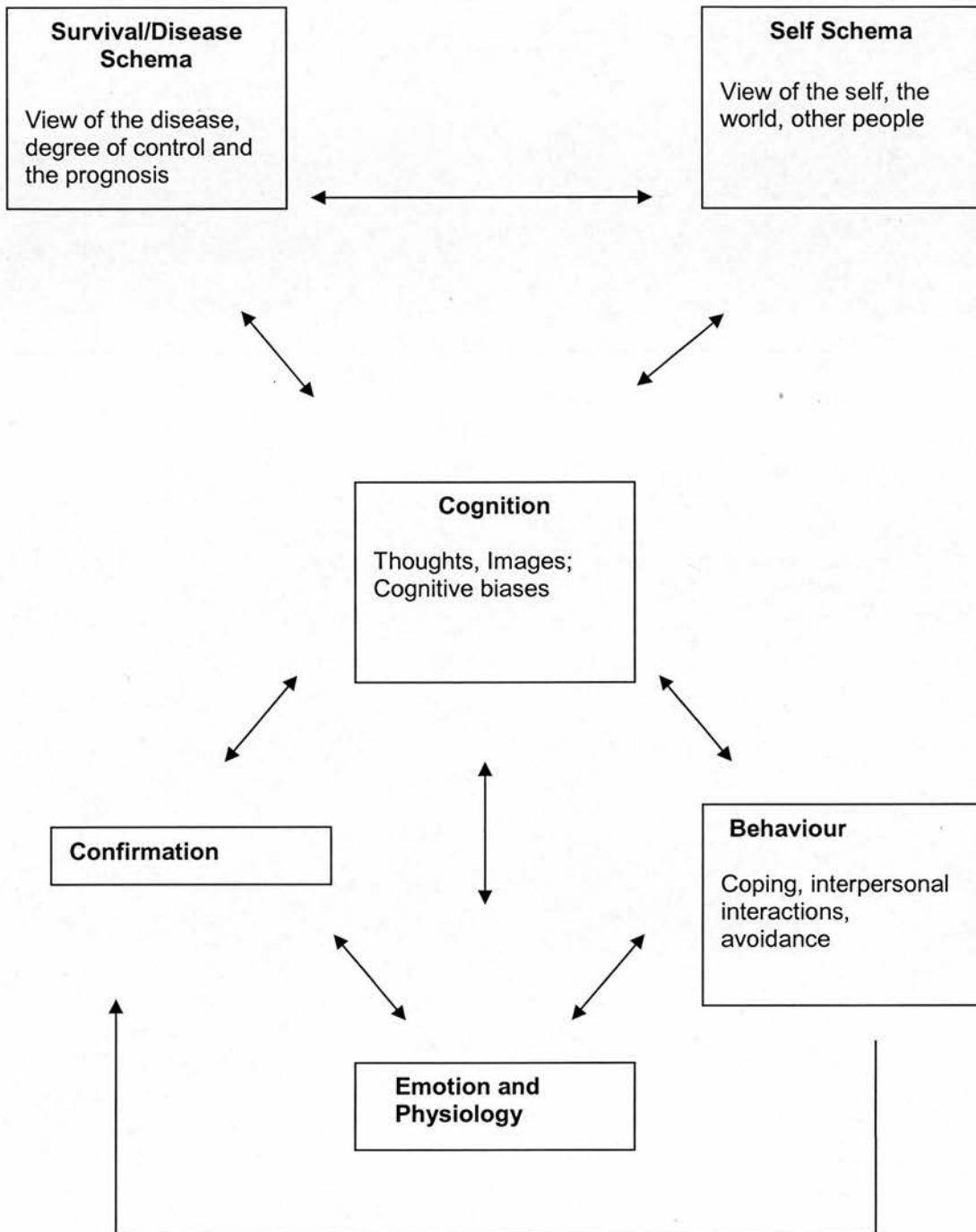
Certain diagnoses and treatments are associated with higher than average levels of psychological problems. In particular the focus of the present study, those with haematological cancers who have undergone SCT or BMT demonstrate significantly higher levels of psychological distress including depression, anxiety and post traumatic stress disorder (Andrykowski, 1989; Lee *et al.*, 2005; Widows *et al.*, 2000). It may be that those

diagnoses or treatments which are associated with higher levels of psychological distress result in more stressors to be overcome than others, thereby providing more opportunity for problematic adjustment to occur.

### **1.2.13. Cognitive Model of Coping and Psychological Adjustment to Cancer**

Cognitive models of coping with stress (Lazarus & Folkman, 1984; Folkman, 1997) propose that it is not the stressful event but the meaning or interpretation of this which determines our psychological adjustment. Certain events such as a diagnosis of a life threatening illness like cancer are likely to challenge our fundamental assumptions and the sense of meaning we make of the world, in particular our beliefs about our very existence and our sense of self (Moorey & Greer, 2002).

Moorey and Greer, (2002) propose a cognitive model of psychological adjustment to cancer based on aspects of Lazarus and Folkman's (1984) model of stress and coping and Beck *et al.*' (1979) cognitive model of depression. Psychological adjustment to cancer is conceptualised in this model as a dynamic interaction between individual appraisal of the meaning of illness and emotional and behavioural responses. Appraisal is shaped by schemata, stable cognitive structures formed in early life providing a mechanism for processing and manipulating perceptual information, schema may be latent until triggered by particular events or situations such as a diagnosis of cancer (Beck *et al.*, 1979). Schemata considered to be of most relevance to adjustment to cancer are survival schema and self schema (Moorey & Greer, 2002). Figure 3 shows a diagrammatic representation of this model.



**Figure 3: Diagrammatic Representation of Cognitive Model of Adjustment to Cancer (Moorey and Greer, 2002,p20)**

## **Survival Schema**

It is likely that such a diagnosis challenges the beliefs patients' possess about future self and mortality. Therefore a diagnosis of cancer is likely to be primarily appraised as a threat, precipitating the stress and coping process. Primary appraisal of the threat to survival posed by the disease may be:

- A challenge to be overcome;
- A threat;
- Potential harm , loss or defeat ;
- Denied.

Following primary appraisal, secondary appraisal is the perception of what can be done to manage or reduce the threat posed (the coping process). This is dependent on factors such as prognosis and treatment options as well as individual belief about the extent to which the disease can be controlled or cured.

## **Self Schema**

In addition to the threat to survival, diagnosis of cancer alters an individual's sense of self. Symptoms and treatment may result in significant threats and losses or changes to most aspects of life that an individual perceives as personally meaningful. For instance, changes to physical appearance and functioning, loss of meaningful activities or roles such as employment, loss of financial security, loss of future self and life plans such as having children.

Moorey and Greer (2002) term these 'threats to self' or 'threats to the personal domain', and suggest that appraisal of these impacts on the emotional reaction of an individual to their illness depending on what meaning is attributed to them. Potentially maladaptive emotional responses are categorised as:

1. Anxiety: results from a perception of danger, that is, that the situation poses a threat or if the individual perceives that others will not deal with real or potential threats.



2. Anger: results when an individual perceives that they have been attacked or have experienced injustice, it is thought that anger reduces experience of emotional distress by externalising focus.
3. Guilt: related to self blame and responsibility, frequently accompanying depression.
4. Depression: associated with loss, Moorey and Greer (2002) highlight that although cancer is frequently accompanied by the experience of loss, depression only occurs when the loss is perceived as being personally significant and is of something valued.

Thus appraisal shapes the cognitions, emotional response and behaviours the individual utilises to manage their illness. However disease characteristics (including treatment and its associated side effects) also contribute to the individuals self perception and directly influence and limit behavioural and functional capacity.

#### **1.2.14. Social Support and Cancer**

Research suggests that social support is relevant to coping with cancer (Stanton *et al.*, 2001). For example Arora *et al.*, (2007) evaluated the perceived helpfulness and impact of social support provided by friends, family and health care providers to women with newly diagnosed breast cancer. The majority of women participating in the study perceived that they had received helpful emotional support from friends and family and helpful informational and emotional support from health care providers following their diagnosis. Emotional support at baseline and emotional and informational support at five post-diagnosis months were significantly associated with better adjustment to their illness.

Emotional support for cancer patients is often dependent on the ability of the family system to provide the level and quality of support desired (Ashby-Wills & Filer-Fegan, 2001) and tends to decrease over time (Arora *et al.*, 2007). It is possible that the level of demand placed on family and friends both emotionally and practically may negatively impact on their psychological adjustment (Moorey & Greer, 2002). Psychological interventions incorporating social support from staff and fellow patients have demonstrated that this is

linked to reduced psychological distress and increased survival 6 years post intervention (Fawzy *et al.*, 1990; Fawzy *et al.*, 1993).

### **1.2.15. Coping with the stress of SCT**

The issues relevant to psychological adjustment and coping with cancer in general are germane to those undergoing SCT for haematological malignancy. However, they face an additional range of stressors related to the procedure itself.

One paper purports to describe a conceptual understanding of the psychological adjustment and coping among SCT recipients and cancer patients. Molassiotis (1997) suggests that SCT should be conceptualised in the context of a cognitive mediational model of stress and coping as proposed by Lazarus and Folkman (1984). However, it is somewhat unclear from this paper the specific relevance of the model to the experience of SCT, rather Molassiotis focuses on the experience of diagnosis of life threatening disease as activating the stress response as opposed to providing a specific theoretical explanation of coping with the transplant process.

Although psychological issues are pertinent to all stages of the procedure, those of most relevance to the present study are those relating to hospitalisation for the procedure and post-transplantation recovery. Table 2 shows psychological and social issues relating to these stages of transplantation.



**Table 2. Psychological and Social Issues related to each stage of Stem Cell Transplantation (adapted from Andrykowski and McQuellon, 1999)**

Stage	Issues
Pre-transplant hospitalisation	<p>Theme: aggressive treatment</p> <p>Managing acute treatment side effects</p> <p>Adapting to isolation and hospital routine</p> <p>Maintaining moral and hope</p> <p>Confronting unfamiliar procedures and treatment (e.g. total body irradiation)</p> <p>Separation from family and friends</p> <p>Altered body image with Hickman catheter</p>
Post-transplant hospitalisation	<p>Theme: watchful waiting</p> <p>Waiting for engraftment</p> <p>Heightened physical and emotional vulnerability</p> <p>Contending with the boredom of isolation</p> <p>Dealing with life threatening complications</p> <p>Encountering acute psychological distress</p> <p>Managing discouragement</p>
Discharge and early recovery	<p>Theme: transition from intense medical surveillance</p> <p>Managing the loss of daily psychosocial support of the medical team and allied health care professionals (e.g. pastoral care)</p> <p>Contending with the stress of frequent medical appointments, readmissions and setbacks</p> <p>Managing unexpected sequelae (e.g. profound fatigue)</p> <p>Adapting to potential frustration, depressive symptoms and anger</p> <p>Complying with self care guidelines and daily medical regimen</p>
Long-term recovery	<p>Theme: re-adaptation to a normal life</p> <p>Full recovery of valued roles</p> <p>Adjust to losses associated with transplantation, e.g. fertility</p> <p>Return to employment</p> <p>Accepting to the possibility and reality of long-term effects (e.g. cataracts, second malignancies)</p>

Adoption of a non-patient identity
------------------------------------

During admission for the procedure potential sources of stress include adapting to hospital routines and staff, the confinement of isolation, protracted duration hospitalisation and the debilitating and life threatening physical side effects (Andrykowski & McQuellon, 1999). Following transplantation recipients need to cope with the challenges of returning home including, frequent hospital appointments and readmissions due to complications such as infection. The psychological experience of discharge home is often dualistic in nature. On the one hand recipients are desperate to leave the confinement of isolation, on the other they may be anxious about the sudden loss of intensive medical support (Andrykowski & McQuellon, 1999).

In the longer term, returning to normality is viewed by participants as a valued goal of recovery from SCT (Andrykowski *et al.*, 1995). However, returning to the pre-illness self is often not possible even in the absence of disease (Andrykowski & McQuellon, 1999; Andrykowski *et al.*, 2005). Failure to cope with any of the demands of the procedure, or violations in the expectation of returning to normal (such as ongoing side effects) can precipitate problems with psychological adjustment such as anxiety and depression.

Two studies have been published which specifically discuss coping strategies utilised by transplant recipients (Molassiotis *et al.*, 1996; Fife *et al.*, 2000). Cognitive coping strategies used by transplant recipients at baseline have clinical utility in predicting emotional response post-transplant. Avoidant coping strategies are associated with significant levels of anxiety and depression, whilst positive cognitive coping strategies such as positive cognitive reframing were associated with low levels of anxiety and depression (Fife *et al.*, 2000).

Transplant recipients used multiple strategies to cope with the hospital admission and associated isolation (Molassiotis *et al.*, 1996). The main strategies include distraction or diverting attention from the situation, talking to family and friends about the situation, acceptance, attempting to maintain some control over the situation and maintaining hope that the situation would get better. Approximately 40 % of participants indicated that they coped with isolation through crying and becoming depressed. Distraction, acceptance, maintaining hope and attempting to maintain some control over the situation were strategies more frequently utilised by those who were less likely to be clinically depressed or anxious post-transplant.

A few studies have examined the influence of social support on the psychological impact and coping with transplant (Bressi *et al.*, 1997; Colon *et al.*, 1991; Molassiotis *et al.*, 1997; Rodrigue *et al.*, 1999; Syrjala *et al.*, 1993). Transplant recipients perceive that they receive more support than those receiving maintenance chemotherapy, sources of support identified were immediate family members and spouses, friends and in particular nursing staff (Molassiotis *et al.*, 1997). Low social support is associated with poorer adjustment including increased PTSD symptoms, particularly for recipients with poor prognosis (Rodrigue *et al.*, 1999, Widows *et al.*, 2000). Higher levels of perceived and consistent social support are related to increased post-transplant survival, improved quality of life and better psychological adjustment (Colon *et al.*, 1991; Rodrigue *et al.*, 1999).

### **1.2.16. Summary**

The evidence considered suggests that diagnosis of cancer is a psychologically distressing event. Most individuals adjust to their illness, however a considerable minority will develop clinically significant problems such as anxiety and depression. Certain diagnoses and treatments e.g SCT and BMT are associated with higher levels of distress. It has been suggested that coping with cancer diagnosis and treatment can be conceptualised as an amalgamation of aspects of Lazarus and Folkmans' (1984) cognitive mediational model of coping with stress and Beck *et als*' (1979) model of depression (Moorey & Greer, 2002). That is, coping and psychological adjustment to cancer involves an interaction between a situational stress response and cognitive schemata, in particular the threat to survival and threat to self. This model is similar to the general model of coping with stress proposed by Folkman (1997) and Park and Folkman (1997). In addition to individual appraisal and behaviour, coping and psychological adjustment to cancer is influenced by social support, in particular emotional support.

Evidence specifically relating to coping with SCT and BMT is very limited. One paper has been published which aims to describe a conceptual model of coping with transplantation (Molassiotis, 1997). This suggests that the cognitive mediational model of coping with stress (Lazarus & Folkman, 1984) is appropriate to coping with this experience; however this paper lacks specificity to the population. Transplant recipients experience a number of stressors and threats to survival, two studies outline coping strategies associated with psychological adjustment and coping during hospitalisation for the procedure. These include cognitive reappraisal, distraction, acceptance and attempting to increase perceived control over the

situation. Avoidant coping strategies are associated with anxiety and depression. High levels of perceived social support are associated with improved psychological adjustment. All of this suggests that a cognitive mediational model of coping with transplantation may be appropriate. However, at present there are no published studies which have investigated this. The limited research specifically addressing coping is questionnaire based and utilises preconceived measures of coping, in the absence of an established conceptual model of coping with transplant, these may not accurately reflect the experience of transplant recipients and may fail to address critical factors.

### **1.2.17. Summary of Section**

Section two provides an overview of theoretical models of coping with stress, psychological adjustment to cancer and coping with SCT. This section has concluded that psychological models of coping suggest that individual appraisal of an event and the meaning that the individual places on this appraisal are integral to the process of coping with a stressor. This is relevant to psychological adjustment to and coping with cancer and may have relevance to the experience of coping with transplantation. However, the section has raised queries about the ability of the current evidence base in providing understanding of the phenomenon of psychological experience of transplantation and coping with this procedure.

## **1.3. Transplant Services**

Section three provides an overview of the national context of SCT and the provision of psychological support within this context, before moving on to provide details of the participating centre and the clinical psychology service provided in this context. Finally an evaluation of this service is outlined in brief. This is done to provide a context for the present study.

### **Stem Cell and Bone Marrow Transplants: Services**

SCT and BMT are highly specialised medical procedures. Autograft transplants are provided within level 3 services. Centres that provide both autograft and allograft transplants are Level 4 services (NICE, 2003). Currently 30 Level 4 centres offer both auto and allograft transplants in England and Wales, there are 4 transplant centres in Scotland.



Given the relationship between this procedure and psychological distress, the National Institute for Clinical Excellence (2003) recommends that all haemato-oncology multi-disciplinary teams should have access to specialist staff to support recipients going through treatment. This includes a clinical psychologist or liaison psychiatrist. In particular, the NICE guideline recommends that where a hospital provides SCT or BMT services psychological support should be available across the transplant process:

‘Psychological support should be taken into account in decision-making about the appropriateness of transplantation, and psychosocial support should be available for patients and their close family members throughout the period of treatment and isolation. Continuing psychosocial support and rehabilitation may be necessary for an extended period after transplantation.’ (p84)

### **1.3.1. Stem Cell and Bone Marrow Transplants: Local Service**

The participating clinical psychology service and haematology department are located within a general hospital providing a level 4 service, the transplant unit undertakes both autograft and sibling donor allograft transplants. The centre does not carry out unrelated donor allograft transplants. A routine psychological screening of transplant recipients was commenced in April 2004. This service has been provided by the present researcher in her role as a Flexible Clinical Psychology Trainee specialising in Oncology.

Stem Cell and Bone Marrow transplant recipients are referred to the clinical psychology department by the Clinical Nurse Specialist who co-ordinates the transplant process and provides intensive support to this patient group. Recipients meet with a Trainee Clinical Psychologist following their admission to hospital for transplant. This interview consists of a standardised semi-structured interview and collection of quantitative data relating to their current psychological adjustment in the form of the Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983) and the National Comprehensive Cancer Network Distress Thermometer (NCCN, 2000).

Recipients are followed up at 1 month, 3 months, and 6 month and in the case of allograft transplants 12 months post-transplant. At follow up the Clinical Nurse Specialist sends out self completion HADS and NCCN distress thermometer along with a letter providing contact details for the clinical psychology department. Both measures have previously been used in psychological screening with this population (Trask *et al.*, 2002).

### **1.3.2. Evaluation of Local Psychological Screening Service**

An audit of the psychological screening of SCT and BMT recipients was undertaken in 2005 by the present researcher (Scott, 2005, unpublished). The proportion of recipients indicating that they experience significant distress, anxiety and depression prior to transplant was 26.4%, 26.1% and 17.4% respectively. These values were similar to those reported elsewhere within transplant literature (Neitzert *et al.*, 1998). No association was found between the type of transplant and level of distress prior to transplant. Statistical analysis of psychological adjustment across the follow up period was not undertaken due to large amounts of missing data.

Scott (2005) concluded that in-depth assessment of patient's psychological adjustment pre-transplant was warranted. Whilst the measures utilised in psychological screening were of relevance to assessing psychological distress among transplant recipients, Scott suggested that by using measures developed for use in other areas of psychology, key issues relevant to the transplant population may not be assessed i.e. anger. Consequently the study recommended that an in-depth qualitative study exploring recipients experiences undergoing SCT or BMT be conducted with the aim of increasing understanding of the psychological impact of this process and the ways in which individuals cope with this. It was hoped that such a study could potentially identify factors pertinent to clinical practice and improve service delivery. The idea for the present study emerged from this work

### **1.4. Summary of Literature Review**

The present literature review has concluded that SCT is a stressful medical procedure associated with high levels of physical side effects and psychological distress. Raising questions about how the experience of coping with this procedure should be understood and applied to assist recipients clinically, it has suggested that in the absence of explanatory conceptual models and empirical research it may be useful to consider the experience of recipients in relation to existing psychological models of coping with stress and psychological adjustment to cancer.



## **1.5. Research Aims and Methodological Rationale**

The present study is not hypothesis driven but exploratory in nature. By exploring in depth the experience of transplant recipients in terms of coping with the transplant procedure and subsequent recovery, the study aims to improve understanding of how recipients perceive the process and the psychological impact of this. The outcome of such a study could form the basis for further research looking at these variables and has the potential inform clinical practice and service development.

Given the exploratory nature of the study, a qualitative design was felt to be an appropriate methodological approach, with emphasis placed on in-depth phenomenological analysis of interview material. Interpretative Phenomenological Analysis (IPA, Smith, 1996) provides a methodological and epistemological approach suited to addressing these concerns. IPA is a qualitative analytical approach to research design and analysis which is not hypothesis driven (Reid *et al.*, 2005), seeking through thorough analysis of individual accounts to identify the meaning attributed to their experience; comparison between individuals may identify collective experience of a phenomenon. Emergent themes can subsequently be compared with existent theoretical and empirical research, providing support for this literature or suggesting areas for further exploration. Additionally participants would complete measures of psychological adjustment providing a description of the characteristics of the sample as a form of methodological triangulation.

## **1.6. Research Questions**

### **Research Question:**

- What is the subjective experience of transplant recipients in relation to coping with the transplant process?

### **Subsidiary Research Objectives:**

- To contextualise participants' accounts by providing a description of psychological functioning on established measures as a form of methodological triangulation.

- To identify factors within participants' accounts relevant to existing literature relating to psychological impact and adjustment to SCT/BMT.
- To identify factors within participants' accounts relevant to existing conceptual models of coping with stress and cancer.
- To identify ways in which the outcome of the study could usefully inform clinical practice.

## **2. METHODOLOGY**

### **2.1. Design**

The present study utilises a retrospective, cross-sectional qualitative design to explore the experience of patients who had undergone SCT or BMT as a treatment for haematological malignancy during 2005 or 2006. Semi-structured interviews were conducted using the format prescribed by Smith (1995) and Smith *et al.*, (1999), data was analysed using Interpretative Phenomenological Analysis (Smith, 1996). Additionally, participants completed two measures of psychological adjustment: the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) and the Mental Adjustment to Cancer Scale (Watson *et al.*, 1988). These measures were included as a means of describing the sample in terms of present emotional functioning.

### **2.2. Reflective Preface**

The topic of coping with Bone Marrow or Stem Cell transplant was selected for the present study. Principally the decision came out of direct clinical experience of working with transplant recipients, undertaken as part of my working component as a flexible clinical psychology trainee, specialising in Oncology. Transplant offers the potential to control or cure a life threatening disease but this outcome is uncertain and the procedure may kill you.

I wondered what the experience of coping with transplantation was like, and how individuals successfully cope with the stresses associated with this procedure. The current literature base did not adequately answer these questions. Literature consistently documents that transplant recipient's experience substantial psychological distress but does not explain why they are distressed. A limited amount of qualitative research had been undertaken exploring quality of life post transplantation but no one appeared to have asked recipients what their experience of the procedure itself was like and what the key aspects to coping with it were. The current study emerged as an attempt to explore and begin to understand this process in more depth.

In keeping with good practice for qualitative research (Elliot *et al.*, 1999) a reflective diary was maintained throughout the study duration. This contained my thoughts about the experience of conducting the research study, my potential influence and about the impact of the process on myself.

## **2.3. Preparation for study**

### **2.3.1. Literature Search and Review**

A literature search was undertaken both electronically and by hand with the purpose of identifying relevant literature and establishing the current evidence base in relation to psychological adjustment to stem cell and bone marrow transplant. The initial search focused on identification of relevant literature published between 1985 and 2007. In addition to establishing an up to date knowledge of the field, this facilitated detection of key papers published outwith this timeframe. This literature informs the study design and introductory chapter.

Key words and terms used singularly and in combination were:

- Stem Cell Transplant/ Transplantation;
- Bone Marrow Transplant/ Transplantation;
- Side effects;
- Psychological Adjustment;
- Stress;
- Coping;
- Cancer ;
- Haematological;
- Depression;
- Anxiety;
- Trauma;
- Quality of life;

Electronic searches were conducted using the following databases: OVID, PubMed, Cancerlit, CINAHL as well as both the NHS Scotland Elibrary and University of Edinburgh Library search engines.

In addition hand searches were conducted on the following journals: Bone Marrow Transplantation, Psycho-oncology

## **2.4. Ethical Considerations**

In addition to NHS research ethics committee guidelines, the study design was developed to comply with the British Psychological Society (2004, 2006) guidelines on ethical conduct and conduct of research within the National Health Service. Consideration was given to the prevention of or undoing of any harm or distress that participation in the study may cause. The following section outlines procedures taken to address ethical issues.

### **2.4.1. Informed Consent**

Following agreement of the participating haematology department, potential participants were identified in discussion with the Clinical Nurse Specialist specialising in transplantation. Individuals were excluded if they had relapsed disease and were judged to be too ill to participate. Potential participants were sent written information outlining the rationale of the study and measures taken to protect confidentiality and address distress (See Appendix 1). Written information was sent with an invitation to participate and a form to be returned, in a stamped addressed envelope, to the researcher granting the researcher permission to contact interested individuals by telephone to discuss the study further. This conversation provided potential participants with an opportunity to discuss in detail the procedure for the study and an opportunity to ask questions prior to giving consent. Once participants opted to participate in the study, the location and timing of the interview was determined by the participant.

Prior to commencing the interview the researcher clarified that participants were aware of the voluntary nature of their contribution and consequently their right to withdraw from the study at any point. It was also emphasised that they had the right to access records of their contribution and to request that these be destroyed without this having any negative consequences on their treatment. Participants were also informed of the confidential nature of their contribution, and the steps taken by the researcher to protect this confidentiality.



Participants were asked to sign a form indicating that they were giving their informed consent to participation in the study (Appendix 2).

#### **2.4.2. Prevention and Management of Emotional Distress**

Procedures were put in place for any participant who may become distressed before, during or after the interview and/or demonstrated problems with psychological adjustment. The information sheet provided to recipients outlined the steps that would be taken in this situation. These included the provision of psychological support by the researcher throughout the interview and notifying their Consultant, GP, Clinical Nurse Specialist and participating clinical psychology service post interview.

Given the exploratory nature of the interview and the topic of research, there was a potential for participants to become emotionally distressed, consequently at any point participants or the researcher could stop the interview. If both researcher and participant agreed that this was appropriate and unlikely to result in psychological harm, interviews would be recommenced. Time was spent with participants following completion of the interview to give them an opportunity to discuss the experience of participating in the study, during which they were encouraged to ask questions. Participants were offered a copy of their interview transcript and asked whether they would like information on the study findings once the study was complete. On cessation of the interview, all participants were offered the opportunity to meet with a clinical psychologist (not the present researcher) for assessment.

#### **2.4.3. Confidentiality**

To ensure confidentiality and reassure participants; all data, informed consent and information sheets were assigned a numerical code, which ensured that individuals could not be identified by a third party. Codes on returned consent forms matched those held on a master list by the researcher to which names of participants were added. This code was attached to recorded interviews and subsequent transcripts.

#### **2.4.4. Data Storage**

The informed consent forms, questionnaires, data recordings and master list were stored separately in a locked cabinet to which only the researcher and clinical supervisor had



access. Data collected was stored in locked cabinets, accessible only to the researcher and supervisor. Electronic information was stored on a laptop computer which was password protected and accessible only to the researcher.

### **2.5.5. Emotional Impact on Researcher**

Due to the potentially distressing nature of participants' accounts or concerns raised about psychological adjustment of participants during interviews, access to clinical colleagues for advice and regular clinical supervision was arranged.

### **2.6. Ethical Approval**

Ethical approval to proceed was received prior to commencement of data collection from both the Local NHS Research Ethics Committee and Health Board Research and Development Department (Appendix 3).

### **2.7. Participants**

Participants were adults who had undergone autograft or allograft stem cell or bone marrow transplant between January 2005 and December 2006 to treat haematological malignancy. Transplants were undertaken within the participating haematology department and participants were continuing to receive post-transplant follow-up care from this department. Individuals were excluded from the study if they had a significant disability unrelated to their cancer or had relapsed disease and were judged to be too unwell to participate. Participants did not have to be fluent English speakers as an interpreter could be arranged.

#### **2.7.1. Recruitment of Participants**

A total of 76 individuals underwent stem cell or bone marrow transplantation during the period of January 2005 to December 2006 in the participating service. See table 3 for further details of all transplants in 2005 and 2006. Discussion with the Clinical Nurse Specialist associated with the transplant service revealed that 19 of these individuals had since died and that a further three individuals had significant relapse of disease and were deemed to be too physically unwell to participate and were excluded from the recruitment phase of the study. Of the remaining 54 transplant recipients, 33 individuals were continuing to receive post-

transplant follow-up care from the participating department and were eligible to participate. These individuals were invited by letter to participate in the study.

**Table 3: details of all transplants (2005 & 2006)**

Year	No of Transplants	No of Allograft	No of Autograft	Deceased	Relapsed
2005	39	14	25	15	1
2006	37	8	29	4	2
Total	76	22	54	19	3

### **2.7.2. Characteristics of Participants**

Of the 33 individuals contacted, responses were received from 12 individuals (36%). Nine consented to discuss the study in further depth, with the other three indicating that they did not wish to participate. The nine individuals who consented to further contact all agreed to participate in the study following a telephone conversation with the researcher. However two of these individuals subsequently dropped out of the study prior to interview and one further participant was excluded on ethical grounds.

The individual excluded on the basis of ethical grounds had developed severe graft versus host disease prior to the scheduled interview and was additionally experiencing low mood and significant psychological distress. Prioritising clinical need a decision was made following discussion with the study's clinical supervisor to withdraw their participation in the study in order that the researcher could meet with them in a clinical capacity.

Data collection proceeded with the remaining 6 participants. The characteristics of which are outlined in table 4.

**Table 4: Clinical & Demographic Characteristics of the sample**

Participant	Gender	Age	Transplant	Year
Robert	Male	40	Autograft SCT	2006
Sarah	Female	33	Allograft SCT	2006
David	Male	53	Autograft SCT	2006
Adam	Male	33	Autograft SCT	2006
Jenny	Female	45	Autograft SCT	2006
Kate	Female	44	Allograft SCT	2006

Names have been changed and ages altered slightly to protect confidentiality.

## 2.8. Procedure

Participants were given the choice of being interviewed by the researcher at either their home or in the outpatient department of the participating hospital. The location of the interview was determined by the participant. All interviews were conducted one to one by the researcher and varied in duration from 40 minutes to 1 hour and 40 minutes. Following interviews participants completed the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) and the Mental Adjustment to Cancer Scale (Watson *et al.*, 1988). Interviews were recorded using an Olympus WS-320M digital voice recorder and transcribed using an Olympus AS-2300 PC transcription kit. Analysis was facilitated using NVivo 2.0, which was used to store and organise material electronically (QSR, 2002).

## 2.9. Measures of Psychological Adjustment

Measures were administered to provide a description of the emotional functioning of the present sample on validated outcome measures pertaining to psychological distress and adjustment. Measures were selected on the basis that they are currently used in the



participating clinical psychology department as screening measures and have been used in research with this population. Measures were obtained for use in the present study from Measures in Health Psychology: A User's Portfolio (Weinman *et al.*, 1995). This portfolio is owned by the participating clinical psychology department.

### **2.9.1. Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983)**

The HADS is a 14-item self-assessment questionnaire, used to screen for generalised anxiety and depression in a medical setting (Appendix 4). The measure excludes somatic indicators of depression and anxiety that may be confounded by physical ill health. The two subscales incorporate seven items and responses to on each item are scored on a 4-point Likert scale (0-3) and scores range from 0-21 for each scale. Scores below seven on either scale are regarded as normal, from eight to 10 as borderline, over 10 mild and over 16 severe. The measure has been used to screen for psychological distress in both a general cancer population (Moorey *et al.*, 1991) and more specifically within the context of bone marrow transplant (Trask *et al.*, 2002)

### **2.9.2. Mental Adjustment to Cancer (MAC, Watson *et al.*, 1988)**

The MAC is a 40 item, self administered scale which aims to identify the cognitive style of adjustment to cancer (Appendix 5). The scale consists of 5 subscales each pertaining to a particular adjustment style (fighting spirit, helplessness/hopelessness, anxious pre-occupation, fatalistic, avoidance).

Each item is scored on a 4-point Likert scale. Total scores are calculated by adding up the scores for items included in each subscale. Higher scores on each subscale indicate that individual utilises this adjustment style to a greater extent. Watson *et al.* (1989) suggest the utilisation of cut-off scores to define clinically significant problems with adjustment (<47 for fighting spirit, >12 for helpless/hopeless). This has been used previously in research with this population (e.g. Andrykowski *et al.*, 1994).

## **2.10. Description of Qualitative Methodology**

### **2.10.1 Interview Approach**

In the present study it was fundamental to understand participants experience with minimal direction on the part of the researcher. Consequently a semi-structured approach to interviewing was selected. This design enabled the interview to follow the phenomenological position of the participant rather the preconceived ideas of the present researcher (Smith, 1996).

An interview schedule was constructed in advance of data collection (Appendix 6). The questions focused on areas relevant to the research question, principally the recipients' experience of the transplant process and their views on coping with their disease and transplantation. This schedule acted as a guide to the interview and was not intended to be prescriptive, questions were omitted or additional questions asked in light of participants' accounts. Questions were open-ended and relatively neutral in their phrasing, again to minimise the influence of any pre-conceived ideas on the topic possessed by the researcher and encourage the participant to provide a richer account. Questions were generally asked in chronological order, with initial questions focussing on the period preceding transplant, in particular the experience of diagnosis and treatment. Further questions focus on the experience of hospitalisation for transplant, before moving on to discuss how they coped with this and their subsequent discharge home. Final questions relate to the longer term impact of transplantation and coping with this.

The interview schedule was reviewed as part of the process of ethical approval, by the local research ethics committee, as well as members of the haematology team and the study's clinical supervisor. No amendments to the interview schedule were required.

### **2.10.2. Selection of Qualitative Method**

The present study utilised Interpretative Phenomenological Analysis (IPA) to qualitatively analyse verbal accounts of the transplant recipients. Whilst IPA was selected, alternative approaches to qualitative analysis were considered. Ultimately selection of the most appropriate qualitative method relates to questions of epistemology, ontology and the research aims. Whilst it is not possible within the restrictions of the present study to provide

a comprehensive overview of each of these techniques, the following provides a brief overview and the rationale for selection of IPA in the present study.

### **Discourse Analysis**

Discourse analytical techniques involve the exploration of transcripts for dominant discourses, and how participants position themselves in relation to these (Potter & Wetherall, 1987). However, this approach assumes that meaning is socially constructed in interaction and that the language people use in a conversation does not necessarily reflect their thoughts or a social reality (Dallos & Vetere, 2005). As the focus of the present study is the perception of recipients in relation to their experiences of coping with transplant, discourse analysis was rejected in favour of an interpretative theme analysis, such as grounded theory or IPA.

### **Interpretative Theme Analysis**

Dallos and Vetere (2005) use the term interpretative theme analysis to describe two approaches: Grounded Theory and IPA. Interpretative theme analysis is defined as assuming that individuals experience the world in stable ways and that through detailed analysis of data, we are as close to reflecting the reality of cognitions and lived experience as is possible. These approaches acknowledge that in doing so, the researcher's interpretation and subjective viewpoint are integral to the analytical process and outcome.

### **Grounded Theory**

Glaser and Strauss (1967) developed grounded theory, which attempts to generate theory based on themes emergent from the data. Theories are thus 'grounded' in the data. Generally such theories aim to extrapolate beyond the individuals participating in the study and thus make claims to generalisability. Underlying this is the philosophical stance that it is possible to generate theories which can explain broader aspects of human experience and behaviour.

### **IPA**

First proposed by Smith (1996), IPA attempts, through systematic thematic analysis of interview material to capture the ways in which individuals understand and make sense of a particular subject or experience. It takes a phenomenological stance wherein the participant



is viewed as the expert on the topic of interest; however research outcomes are an interactive process. The researcher must interpret accounts and in doing so will influence the analytical outcome.

### **Selection of IPA**

Although the approaches share some similarities, IPA was selected rather than grounded theory (Glaser & Strauss, 1967). Both utilise similar analytical techniques (Smith *et al.*, 1999; Willig 2001; Dallos & Vetere, 2005), including semi-structured or open interviews, systematic analysis and integration of individual accounts to provide a detailed thematic analysis of a phenomena. Neither approach is initially hypothesis driven, however hypotheses may be generated from analysis of initial accounts in a grounded theory and subsequently tested and refined through further data collection and analysis.

A number of variants of grounded theory exist (Braun & Clarke, 2006; Willig 2001). Willig (2001) suggests researchers familiarise themselves with these and the debates surrounding them before selecting the version most appropriate to the research question. There is at present little variability in how IPA has been utilised (Braun & Clarke, 2006), therefore it may be a particularly suitable approach for the novice qualitative researcher. Additionally, IPA may be a preferable to Grounded Theory if the research aims to relate emergent themes to existing literature as opposed to generating theory (Dallos & Vetere, 2005). IPA has increasingly been used in applied health research, in particular to understand the psychological experience of recipients (Reid *et al.*, 2005) and has been used to explore the meaning of the concept of quality of life to SCT and BMT survivors (Holmes *et al.*, 1997).

Therefore IPA was felt to be a suitable methodological approach for the present study, enabling a comparison with existing literature and providing an in-depth analysis of the experience of transplant recipients in relation to coping with the procedure.

### **2.11. Interpretative Phenomenological Analysis: Description of Method**

The roots of IPA are in the phenomenological school of philosophy and psychology, consequently a series of assumptions about the nature of knowledge and the function of language underpin this approach. Phenomenology developed from the work of Husserl (Davies & Bhugra, 2004), and relates to the ways in which we attribute meaning to the

world. In particular, the manner in which individual meaning is consciously attributed and the ways in which this is subjectively experienced. How we act is dependent on the meaning that we attribute to our experience. These meanings are socially constructed and are maintained through interaction and ongoing appraisal of the word (Davies & Bhugra, 2004).

In keeping with a phenomenological position, IPA aims to provide a detailed description of conscious experience. As it is not possible to directly access perception, the language used to describe a situation is considered to be referential and consequently an indirect measure of cognition (Smith *et al.*, 1999). Thus the method may have potential utility for clinical psychology research as the underlying philosophy fits with social-cognitive models of psychopathology and psychotherapy (Smith, 1996; Smith *et al.*, 1999). Through analysis of verbal accounts IPA aims to identify and explore the meaning of experience to an individual. As this process requires interpretation of the meaning by the researcher, IPA is an interpretative approach to the phenomenological position of the research participant.

While IPA treats the individuals account and beliefs as unique, it has utility in comparing the experience of a number of individuals in relation to particular phenomena such as an illness or treatment and establishes whether there are generalisable aspects of experience. Reid *et al.*, (2005) highlight the utility of an IPA approach in enabling a means of accessing the perspectives of service users.

## **2.12. Quality of Research**

In contrast to quantitative empirical approaches to research and data analysis, IPA is based on qualitative epistemological assumptions. Rather than seeking to establish accurate measurement and statistical analysis of causal relationships through hypotheses, qualitative methodologies attempt to illuminate our understanding of the meaning of phenomena for individuals or groups. Different criteria are used to evaluate the standard of qualitative research (Elliot *et al.*, 1999) and criteria for establishing validity, reliability and generalisability (Malterund, 2001). Malterund (2001) suggests that validity, relevance, and transferability are the qualitative equivalents. These concepts and the issue of sample size are outlined below, along with steps taken to address them.

### **2.12.1. Validity**

Internal validity relates to the extent that a study examines what it purports to (Malterund, 2001). Rigour underpins the internal validity of a qualitative approach. Rigour is defined as a systematic approach to analysis, sufficient detail of analysis and the detail of what is presented to the reader. The analysis should be transparent; with interpretations clearly supported by examples from the data which should present a compelling and therefore valid account of the phenomenon under investigation (Taylor, 2001).

Applying a theoretical framework to qualitative analysis e.g. IPA enhances the rigour and internal validity of a study (Braun & Clarke, 2006). To ensure competence in the skills required to undertake a qualitative study using IPA, the researcher attended a one day workshop run by a researcher experienced in using the method. This covered theoretical and practical application of IPA, including research design, recruitment, interviewing skill and analytical technique.

Transparency of analysis in the present study is ensured by providing a detailed outline of the analytical strategy supporting analysis with quotations from participants' accounts. Additionally, as a credibility check (Elliot *et al.*, 1999) thematic analysis on a sample of transcripts was undertaken by an external party (n=3). This facilitated discussion of thematic interpretation and clarification of ambiguous coding. This process facilitated reflection on the research process.

Participants also completed the HADS (Zigmond & Snaith, 1983) and the MAC (Watson *et al.*, 1988); these provided a description of psychological functioning of the sample on standardised measures and are a form of methodological triangulation (Elliot *et al.*, 1999). It was hoped that this would enhance understanding and increase transferability of study findings. This was felt to be particularly important in the medical context of the present study as it has been suggested that qualitative research may still be:

'regarded by scepticism by the medical community, accused of its subjective nature and absence of facts' (Malterund, 2001, p483)

### **2.12.2. Transferability**

The concept of transferability has been used as an alternative to the concept of generalisability in qualitative research (Malterund, 2001). Generalisability is a key consideration in terms of the validity of quantitative research and it has been suggested that inappropriate application of this concept has been used to 'castigate qualitative research' (Dallos & Vetere, 2005, p43). Transferability refers to the extent that the findings of a qualitative study can be applied beyond the context of the study. Whilst transferability does not equate to empirical generalisability, it can refer to theoretical generalisability (Dallos & Vetere, 2005). It is possible to theoretically generalise from research findings based on detailed analysis of a case or number of interviews. Research should acknowledge the potential limits of transferability and should utilise appropriate sampling methods to address the research question. Providing adequate detail of the study, ensuring transparency of research assumptions and conduct of research adds to the transferability of research findings (Dallos & Vetere, 2005).

### **2.12.3. Reflexivity**

The influence of the researcher is integral to qualitative research. This is of particular relevance to IPA in which the researcher actively interprets participants' accounts. It is important that the reflexive position of the researcher is clear. Reflexivity is the process by which the researcher acknowledges their own perspective in relation to the research (Elliot *et al.*, 1999). The researcher attempts throughout the process to acknowledge both their impact on the research and the impact of research process on them. A reflexive diary was kept during the present study to enable thoughts about the process and potential influence of the researcher on the research to be documented.

### **2.13.4. Sample Size**

Although IPA can be employed with large samples, smaller sample sizes are recommended to retain idiographic focus and to enable the researcher to fully engage with participants accounts. Qualitative studies should aim for at least five participants (Smith *et al.*, 1999) or seven (+/- 2), giving a range of between five and nine (Dallos & Vetere, 2005). The present study provides an adequate sample for this methodological approach.



## 2.14. Analytical Strategy

A number of strategies are available for conducting IPA (Smith *et al.*, 1999; Willig, 2001), selection of the specific analytical procedure and technique is dependant on the number of narrative accounts to be analysed, the depth of analysis to be conducted and the specific focus of the researcher. Given the limitations of the present study and a focus on the psychological experience of stem cell transplantation both on an idiographic (meanings and interpretations conducted on individual accounts) and group level, an emphasis has been placed on the identification of themes recurrent across the group, relating these back to individual accounts (Smith *et al.*, 1999; Willig, 2001). See table 5 below for a summary of the analytical procedure undertaken.

**Table 5: Summary of analytical procedure**

<b>Analysis of Individual Accounts</b>
1. Tapes were repeatedly listened to and transcribed verbatim.
2. The first interview transcript was read, and reread.
3. Exploratory coding conducted: line by line analysis of the interview.
4. Exploratory codes refined to produce a list of emergent themes.
5. Emergent themes clustered to produce a list of super-ordinate conceptual themes representing the dominant themes in the account.
6. Summary table of super-ordinate themes produced.
7. This process was repeated for subsequent interview transcripts.
<b>Integration of accounts and identification of shared experience</b>
1. Summary tables of super-ordinate themes for transcript were combined and compared in a group level summary table resulting in identification of shared super-ordinate themes. Each extract was examined for examples of accounts relating to the shared themes.
2. Emphasis was placed on further interpretation and analysis of recurrent/shared themes.

### **2.14.1 Analysis of Individual Accounts**

1. Each tape was listened to repeatedly and transcribed verbatim. Transcription was comprehensive, including pauses and features relating to language use such as laughter, repetition of words and incomplete sentences. Participants' use of local dialect and colloquialism was retained to maintain the authenticity of the account and analysis. Transcripts were cross checked against the tape to ensure accuracy.
2. The first transcript was read and reread. Notes were produced during this initial engagement with the text. These notes summarised thoughts, ideas and questions.
3. Analysis of each line of the transcript was conducted, leading to the production of exploratory codes. Three aspects of the text were the focus of this analysis: the description and content of what was said, how this was said and initial conceptual interpretation of this (See Appendix 7, for a sample of transcription and coding).
4. Exploratory codes were refined to produce a list of emergent themes, which represent the data at a conceptual level. This list was cross checked against original transcript.
5. Potential relationships between emergent themes were explored, focusing on creating super-ordinate codes incorporating clusters or hierarchical organisation of initial themes. These were then cross checked against the transcript to ensure that they related to the text.
6. Summary table of higher order codes produced, again cross checked against the original transcript and incorporating illustrative examples found in the transcript (including quotation and page/line reference). To ensure that the analysis maintains focus relating to research aims, the summary table only included higher order codes/themes relating to psychological experience and coping with stem cell transplantation.
7. This process was repeated for subsequent interviews.



#### **2.14.2. Integration of Individual Accounts and Identification of Shared Experience**

1. To enable a more generalised understanding of the psychological experience of coping with stem cell transplant, an integration of the higher order themes emergent from individual accounts was undertaken (Smith *et al.*, 1999; Willig, 2001). A summary table reflecting the higher order themes across the corpus was produced, and shared themes identified. Further analysis was undertaken on these shared themes in order to produce final master list of themes and illustrative examples of these taken from individual accounts (See Appendix 8 for a sample of extracts relating to a super-ordinate theme).
2. These master themes and illustrative examples form the basis of the analysis and interpretation of the psychological experience of this group in relation to coping with stem cell transplantation and are presented and discussed in the following results and discussion section of this report.

### **3. RESULTS AND DISCUSSION**

The following section outlines the analysis and results of the present study. This includes a profile of participants, performance on measures of psychological adjustment and interpretative phenomenological analysis of themes emergent from semi-structured interviews. Emergent themes are discussed in relation to existing literature before the findings of the study are summarised and interrelationship between themes discussed.

#### **3.1. Profile of Participants**

Names have been changed to protect confidentiality.

##### **Participant 1: Robert**

Robert underwent an autograft stem cell transplant to treat relapsed Hodgkin's disease in 2006. His transplant was aimed at curing his disease. He is married with two children. Robert was seen prior to transplant as part of routine psychological screening and reported no history of psychological problems prior to his transplant. Post-transplant he sought help from the participating clinical psychology department for problems with anger and low mood following his return to work.

##### **Participant 2: Sarah**

Sarah underwent an allograft stem cell transplant to treat Acute Lymphoblastic Leukaemia in 2006. Her transplant aimed to cure her disease, her prognosis was very poor if she did not undergo transplant. She is single with no children. Her sister was her sibling donor. She reported no history of psychological problems prior to transplant. She was seen by the participating clinical psychology department prior to and throughout her admission for her transplant. Increased psychological support was provided to her during transplantation on the basis that her transplant was likely to be both physically and emotionally demanding due to the aggressive nature of her disease. She has had no contact with the participating clinical psychology department post-transplant.

**Participant 3: David**

David underwent an autograft stem cell transplant in 2006 to treat relapsed Non Hodgkin's Lymphoma. His transplant was aimed at curing his disease. He is married with adult children and has a large number of siblings with whom he is close. David retired from work due to ill health a number of years ago. He has no history of psychological problems and has had no contact with clinical psychology post-transplant.

**Participant 4: Adam**

Adam underwent an autograft stem cell transplant in 2006 for treatment of relapsed Hodgkin's disease. His transplant was aimed at curing his disease. He is married with no children and describes a close relationship with his extended family. He reports no history of psychological problems and has had no contact with the participating clinical psychology department post-transplant.

**Participant 5: Jenny**

Jenny underwent an autograft stem cell transplant in 2006 for treatment of Multiple Myeloma. Her transplant was aimed at increased control of her disease and was not curative. She is married with two adult children. She reported no prior history of psychological problems and has had no contact with the participating clinical psychology department post-transplant.

**Participant 6: Kate**

Kate underwent an allograft transplant in 2006 for treatment of Chronic Myeloid Leukaemia. Her transplant was aimed at curing her disease. She is married with no children. Her sister was her sibling donor. One of her siblings is in full remission from Non Hodgkin's Lymphoma. She reports no history of psychological problems and has had no contact with the participating clinical psychology department post-transplant.

### 3.2. Results

#### 3.2.1. Measures of Psychological Adjustment: profile of participants

Five participants completed both the HADS and MAC following their interview; data is unavailable for one participant. Time since transplantation ranged from 6 months to 16 months, with a mean of 10 months.

#### Hospital Anxiety and Depression Scale (HADS, Zigmund and Snaith,1983)

Both David and Kate score 9 on the HADS anxiety subscale, indicating borderline clinical significance for generalised anxiety. No participants scored within the clinical range for depression. See Table 7 for HADS Anxiety and Depression Scale Scores.

Snaith and Zigmund (1994) suggest that a score on either scale in the range 8 - 10 indicates clinically significant problems at a mild/borderline level, 10 – 15 moderate and 16 or above as severe. However normative data gathered from a large non-clinical sample (n= 1792, Crawford *et al.*, 2001) suggests that a cut-off point of between 8 and 10 may be over-inclusive with 33 % of the population meeting the criteria for clinically significant anxiety or depression. In the general population, 20.6% of the sample score within the mild/borderline range of anxiety, 10% within the moderate and 2.6% severe. For the depression subscale, 7.8 % met criteria for mild depression, 2.9% moderate and 0.7 % severe. Crawford *et al.*, (2001) propose a that a cut off of 10 or 11 be utilised when identifying clinical cases as this is more in line with epidemiological studies of anxiety and depression. Therefore the significance of both David and Kate's scores for generalised anxiety should be interpreted with caution.

**Table 7: Participants' scores on Hospital Anxiety and Depression Scale (HADS)<sup>1</sup>**

HADS Scale	Robert	Sarah	David	Adam	Jenny	Kate
Anxiety	N/A	4	9*	6	2	9*
Depression	N/A	0	6	0	1	2

<sup>1</sup> \* Denotes clinical significance

Psychological screening of transplant recipients in 2005 and 2006<sup>2</sup> within the service in which the current study was based revealed that 50% of recipients who completed and returned the HADS pre-transplant scored above the clinical cut off for generalised anxiety and 21% scored above the cut off for depression. At six months post-transplantation 25% of those responding scored as both clinically anxious and depressed.

### **Mental Adjustment to Cancer Scale (MAC, Watson et al, 1988)**

See Table 8 for participants' scores on the MAC, reported scores are raw scores and are comparable with the mean values and standardised deviations reported by Greer and Watson (1987) and Nordin *et al*, (1999). Fighting spirit and helplessness/hopelessness are inversely related and are considered to be a bi-polar construct (Watson *et al.*, 1988; Weinman *et al.*, 1995). A raw score of less than or equal to 47 on the Fighting Spirit subscale combined with a score of greater than or equal to 12 on Helplessness/Hopelessness subscale indicates clinical significance (Weinman *et al*, 1995). No participant met the clinical case criteria on the MAC, suggesting that they are coping adequately with their cancer diagnosis.

**Table 8: Participants' scores on the Mental Adjustment to Cancer Scale (MAC)**

<b>MAC Scale</b>	<b>Robert</b>	<b>Sarah</b>	<b>David</b>	<b>Adam</b>	<b>Jenny</b>	<b>Kate</b>
Fighting Spirit	N/A	54	51	60	52	54
Helplessness/hopelessness	N/A	7	14	6	20	11
Anxious Preoccupation	N/A	27	23	21	18	20
Fatalism	N/A	18	22	14	16	14
Avoidance	N/A	3	1	2	1	3

### **3.2.2. Interpretative Phenomenological Analysis**

Seven shared super-ordinate themes emerged from analysis of the data:

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<sup>2</sup> Time frame of relevance to the present study

1. Existential Issues
2. Psychological Experience of Transplant Procedure
3. Physical Side Effects
4. Relationships
5. Change of Meaning and Altered Perception of Self
6. Normality
7. Transplant Procedure

Transplant procedure was excluded from further analysis because it was of less relevance to the research focus. The other six super-ordinate themes were selected for further analysis and interpretation. Table 9 presents super-ordinate themes and their interpretative components.

**Table 9: Super-ordinate themes and interpretative components of these**

<b>1. Existential Issues</b>	<b>2. Psychological Experience of Transplant Procedure</b>	<b>3. Physical Side Effects</b>
a) Fear of death b) Hope for survival c) Perceived risk	a) Cognitive appraisal b) Perceived control c) Emotional response	a) Eating problems b) Fatigue c) Hickman Lines
<b>4. Relationships</b>	<b>5. Change of meaning and altered perception of Self</b>	<b>6. Normality</b>
a) Relationships with family b) Relationships with staff c) Impact on family	a) Change of meaning b) Altered perception of self	a) Desire for and expectation of normality b) Violation of expectation of normality

The analysis which follows is organised around the super-ordinate themes emergent from participants' accounts. Analysis of each theme is subdivided into two sections. The first



section provides a description and interpretative analysis of the shared experiences inherent in participants' accounts. Direct quotations are provided to illustrate interpretations of shared themes; these are discussed in relation to the idiographic experiences of participants. Each account is identified by participant and the location of each quotation is identifiable by line number. Within quotes, ellipsis points indicate pauses (...), square brackets indicate the omission of words or lines from material and parentheses enclose non-verbal aspects such as laughter. The second section of each theme considers the implications of this analytical interpretation in relation to existing literature.

### **3.2.2.1. Theme 1: Existential Issues**

#### **Description and Interpretation**

Consideration of existential issues is viewed as part of the experience of coping with Stem Cell Transplant (SCT). Consistently participants expressed fear of dying during the transplant process; this fear was experienced alongside hope for survival; with transplant viewed as both a crisis to be overcome and an opportunity for a new life. Participants also talked about their perceptions of the level of risk involved in undergoing the procedure. Existential issues influenced appraisal of the procedure, in particular the perception of transplant as threat.

#### **a) Fear of Death**

Recognising that death can occur during the transplant process, participants described a period of fear of death both preceding and during their admission to undergo the transplant procedure. This fear was grounded in their expectations and knowledge of the transplant process. It was a real fear, based on their knowledge that transplant has a high mortality and is associated with a number of life threatening complications. In an example of this, Jenny describes learning about the transplant process and the risks involved:

Then I got all the books and things and I was to think about it and then I went up to speak to [name]. Aye so eh the books, when you read the books ken obviously they tell you all the worse scenarios eh... it did worry you a wee bit. (Jenny, 168-172)

In spite of the risk, she is aware that transplant is, for her, the best treatment option. It offers her the best possibility for control of an incurable disease. Her fear appears to be contained by her belief that her doctors are acting in her best interests.

Participants had often met and got to know other recipients going through the process who had later died; this shaped their perceptions of the process and increased their fear of death.

As David recounts:

well just...that many people die ay these things. [ ] but how anybody says it doesnae go through their minds ... it's the first thing that does ... there is always somebody dyin. Kinda bein in there and I soon got to know people and they've died ... it's a hard thing. I mean you know the older you get the percentages are higher for that to happen...it's quite hard (David, 77-81)

The experience of medical complications also increases the salience and reality of fear of death. Sarah gives an account on one such experience in which she develops a life threatening pulmonary thrombosis in the period leading up to her transplant:

I just couldnae breath at all I was just sort ae climbing. I was actually I don't know why but it must just be something but I was actually climbing up the back of a chair...trying to get breath. [...] about four nurses just came charging through and...got me on the bed and sort of got oxygen down me and gave me some valium and that to try and calm me but by that time I thought am a gonner...and I thought I cannae do this in front of my mum (laughs) ah don't know what I was thinking (Sarah, 358-360)

Sarah thinks she is dying; her next thought is that she can't die in front of her mum. Reflecting on her experience, this thought seems humorous to her. As if she is wondering of all the thoughts she could have had when facing her own imminent death, why that one? This account provides a real sense of the acute fear and psychological distress experienced by Sarah. Her experience increased her sense of apprehension and appraisal of transplant as threatening.

## **b) Hope for Survival**

Alongside fear of death, participants simultaneously perceive transplant as a treatment which offers them hope for survival. The traumas inherent in the process can be coped with because of the potential for a new life, a life which is disease free or with improved life expectancy.

In the following extract Sarah captures the experience of hope. Her account shares many of the aspects identified by fellow participants.

I think if they had just said "oh well we will do this and that will give you an extra year of something"...I would have had a serious think about going through it. But I think when they said that when you go through this hopefully that will lead to a cure and speaking to other transplant patients 10 years down the line I know that it is possible. I know that some people do have a relapse but there is hope there that it is...that it is going to work for me basically. (Sarah, 839-846)

In contrast to other participants, Jenny's transplant did not offer her the hope of a cure, only the potential to increase the control of her disease. Yet, she perceives it as having given her the possibility of a longer life and the hope that in this time a cure may be found for her cancer.

Aye...just hoping that I reach my bus pass aye ken... I noticed that there was ain the paper the other day...they have got a new drug for Myeloma. It was my hubby that came hame and said about this new drug but when I read it the bit at the bottom of it said something about ehm something about a year and I thought...I thought it was gan tae be a miracle cure...but its no, its no quite yet. But I suppose they are always bringing things out and ehm its amazing what they can do. (Jenny, 913-921)

### **c) Perceived Risk**

Participants emphasised their perceptions of the risk involved in undergoing SCT. These perceptions were frequently expressed in percentages and related to communication received from medical staff. Participants were not reassured by the levels of risk communicated to them, their fear of death appears to be more salient and risk is perceived in relation to their own anxious attributions of risk to self.

Robert talked about the meaning of risk of the transplant process to him. When the level of risk of death is communicated to him, he converts this. He perceives the risk that he will die as being much greater than that communicated to him, transposing the 2% risk of death to 98%. He relates this to his vulnerability to infection whilst in isolation and the risk he perceives of catching a fatal infection from others.

Somebody said to me...the worst, worst case scenario 2% you could die. Two percent is 98% in my head...you come in here with a cold. It is 98%, get out! That's what you feel like saying to them. (Robert, 1248-1250)

Whilst Robert talked about an inflated perception of risk, David talks about his perception of increased risk due to his age. It may be that this relates to the categorisation of risks into age ranges apparent within medical literature i.e dichotomised >50 and <50.

Because when they tell you the percentages...you can go from 30% to 70% just like that...just depends on your age and things like that ... the penny drops when they speak like that ... when I was under 50 it wisnae so bad. It didnae worry me but the next time when I realised...[ ] I'm over that magic 50...50 year old... now it's no so easy (David, 265-269)

### **Discussion: Existential Issues**

Existential issues were pertinent to all participants; both prior to and during transplantation they experienced a concurrent fear of death and hope for survival. This is consistent with the propositions of existential psychotherapists such as Yalom (1980) and Frankl (1959/2004) who suggest that fear of death is inherently related to the meaning attributed to and experience of life and such concerns become particularly salient when facing life threatening experiences. Existential concerns were shaped by perceptions of the procedure as life threatening, level of risk and potential benefit.

Only one paper has been identified which specifically addresses the topic of death and dying in relation to SCT/BMT (McGrath *et al.*, 2006). However, this study examined the experience of bereaved spouses not the concerns of recipients. Emphasising the role that positive thinking plays during the transplant process and recovery, it was perceived as having both benefits in assisting recipients to cope with process and disadvantages, leading to avoidance of discussions about the possibility of death and planning for such an eventuality. They suggest that failure to address issues of death and dying has a negative psychological impact on bereaved spouses.

No papers have been identified which explicitly investigate the experience of transplant recipients in relation to death and dying. Additionally, research exploring the experiences of those whose disease is unresponsive to treatment or who relapse post-transplantation is virtually nonexistent (Kelly *et al.*, 2000). Kelly *et al* (2000) further comment that failure to explore such issues may disadvantage those who are not cured, a subgroup of recipients who may be the most vulnerable.

Perceptions of disease and treatment shape beliefs regarding transplantation and the aforementioned existential issues. Individuals need to appraise the potential risks (e.g. seriousness and severity of adverse effects; duration of adverse effects; frequency of adverse effects) and balance this against the perceived benefits (e.g. potential for improvement; increased time offered by treatment) (Berry, 2004). The idiosyncratic nature of interpretations based on relative importance and meaning of risk to the individual indicates the importance of cognitive factors and the potential utility of cognitive models for example, Moorey and Greer (2002). Research indicates that interpreting risk when communicated in percentages can be problematic, particularly when it refers to single event probabilities such as death (Berry, 2004). This finding is in agreement with the findings of the present study.

### **3.2.2.2. Theme 2: Psychological Experience of the Transplant Procedure**

#### **Description and Interpretation**

Psychological experience of the transplant procedure cut across participants accounts of their experiences. Cognitive appraisal of the procedure, perceived loss of control, emotional response and rumination were all aspects of this experience regarded by participants as being important to developing an understanding of coping with the process.

#### **a) Cognitive Appraisal of Transplant Procedure**

##### **Appraisal of Process as Threatening**

The process of transplant was invariably regarded by participants as threatening. As Robert describes his experience of admission to the ward in preparation for his transplant, it is apparent that he is apprehensive and anxious. At the point his wife leaves the room he begins to feel unable to cope. His anxiety suggests that he appraises the situation to be a potential threat.

I think just the fact of being away from home...em for 3 or 4 weeks or whatever...just the thought of it...the thought of it just didn't appeal to me. Em I think that by the time I got there...I was prepared...by the time I got in the room I wasn't. I just wasn't ready for it...I hated it...[name] dropped me off



and she had to go to work...and she says right I will see you later...and I thought I'm no looking forward to this at all. So I think that from that point of view there was a slight chink in the armour by that stage...I was starting to worry about it. I didn't know what to expect...ah think in a lot of ways...its better not to know what is going to happen but in some cases they have to kinda let you know what's going to happen with the high dose stuff. (Robert, 332-344)

The appraisal of transplantation as a threat is mirrored by the following account provided by David.

Knowing its just got to work eh, you just don't know it. Apprehension eh ...you're into the unknown its no something that happens to you every day ...your life's in their hands and you're...your saying to yourself...just takes me to pick up a bug or something when you've no immune whatsoever. It's frightening... it's frightening ... as I always say you cannae live your life looking over your shoulder...but you always have a wee look back sometimes ... (both laugh) you can't go through life without looking back at something or other ... A very daunting time... very ... depends on where you are in your own mind I think. Cause if you're very unwell it can be a blur to a lot ay people...but if you're keeping sortay compus mentus... you know what I mean and you'll... you realise more what's going on. ( David, 240-248)

The above account from David links appraisal and emotional experience; how you experience treatment, 'depends on where you are at in your own mind'. David is aware of the physical and psychological demands of transplant and described being more apprehensive and fearful of his transplant due to this awareness. Participants describe the information received prior to transplant as necessary, but it can also shape their perception of the process as a threat to physical and mental wellbeing.

In contrast to David and other participants, Jenny wondered whether her lack of knowledge and uncertainty about the transplant process increased her apprehension.

Ehm... I think it was just getting that huge dose of chemotherapy and the getting they stem cells... it was just that I had never spoken to any body that had actually had the... If I could maybe have spoken to somebody that went through it and they were alright...Id say you know this is okay. But I had never actually spoken to anybody because my doctor hadnae...she had never had a patient...like my [ ] doctor that had stem cells you know. (Jenny, 255-264)

Participant accounts suggest therefore that knowledge of the procedure shapes their appraisal of the transplant procedure and the quality of this appraisal.

## **Positive Reappraisal**

Although participants emphasise that they primarily appraised transplant as a threatening experience, threat is not the sole appraisal. Simultaneous attempts at positive reappraisal of their experience are apparent within their accounts. This is exemplified by the account of Sarah who describes the process of transplantation as being analogous to the redevelopment of a piece of waste ground into a beautiful garden. Not only does this appear to provide her with a way of experiencing her transplant as something positive and hopeful, but it provides a means of creating shared understanding, enabling others to support her.

Was when I first started off I was a waste ground and sort of that was, that was the Leukaemia was kinda like the waste ground and I was like so that was stage 1 and stage 2 was like clearing the piece of wasteland or waste ground and ...and sort of ... turning the soil and what not and getting it ready to be. To get a...a lawn ready and planting seeds was stage 3 which was in relation to my transplant and then once the seeds had been planted you had to water the lawn and that was once the transplant had been done I then had to water the lawn and let the grass grow and then once I was at the end of it there was going to be a beautiful garden so they had transferred this wasteland into a this garden.

That's the way I sort of got it, so I think I was telling my friends and that my story and that kinda got in my head so they used to say to me right you have to get to the, you have to get to the this planting of the seeds and then the watering of the garden that's a doddle. Eh and I was like yeah, so that's the way I always kept it in my mind that I need to get to the watering. (Sarah, 388-415)

A further example of positive reappraisal is provided by Jenny, she describes the process of retrospective positive reappraisal as part of her recovery from her transplant. She is reflecting on the disparity between her current recollections of the process and the accounts she has written in her diary:

Because after a while when you get better you think ah it was fine...it wasnae as bad as I thought it was...but then when I look back in this ah think it was horrible...it was bad. It was (sighs) (Jenny, 454-459)

When reflecting back on her experience, it is positively reappraised, it is only when reading an account written contemporaneous to transplant that she recollects how difficult the procedure was to endure. This is interesting, in that Jenny is the sole participant who potentially faces a second transplant to control her disease. It may be that her positive reappraisal functions as a way of coping with the potential threat of a future transplant.

### **c) Perceived Loss of Control**

#### **Loss of Control**

As participants described experiences of coping with hospitalisation for transplant, perceived loss of control dominated their accounts. Although the loss of control experienced by those undergoing stem cell transplants is very real, it appears to be their perceptions of this and attempts to modify these which relates to their psychological experience of transplantation. Being nursed in isolation was associated with acute psychological distress, feelings of confinement, loss of freedom and desperation to leave. Frequently participants used the analogy of a criminal confined to prison to describe their experience. An exemplar of this is provided by Robert:

You have had the chemo and you have got out and then the next day you have got the stem cells back and from then on in that's it you're not allowed out... folk tell you that you cant do something...you want to automatically do it... you want to go and walk out...you know you cant...you know you cant...for your own sake but its like being in prison. I could not commit a crime...ah would hate to spend my life in prison...it would drive me up the wall. (Robert, 388-395)

Robert feels trapped in isolation. He wants to leave but is aware that he can't - the consequences of leaving would be worse than enduring his psychological distress. This experience was common. As described by Sarah:

I think from day one... you just wanted to leave but it's hard because its no like you are in a prison cell but you cant leave. But you can't leave... you know because medically it... you would even probably die or you would get such a bad infection (Sarah, 1099-1102)

The perception of loss of control is not limited to control over environment, it is also linked to loss of control over the self. Participants described the transplant procedure as creating dependence on others, reducing their perception of control further. Kate talks about the extent of this dependence as she is literally placing her life in other's hands, and perceives herself as having lost total control:

you know you're going to be in that room and you can't come out of it. That ... you don't realise ... well I didn't realise what that meant until I was actually

there and you had to be dependent on people like if you wanted something. If you needed help with anything and that or ... just the silly things, like ... you weren't in charge of your own life... you were putting your life... I was putting my life in their hands ... that was really alien to me. It was difficult I think ...It took a wee while to grasp that. I was doing things and they were like "no you've not to do that". I was making my bed and they were like "no you've not to do that will you just leave it"...after wee while I didn't do it and I didn't feel like doin it but ... it took me a wee while just to step back and let people do things for me. (Kate, 163-171)

The dependence she feels on others is psychologically difficult for Kate; it challenges her belief that she is an independent and capable woman. She attempts to increase her perception of control by continuing to undertake self care tasks, even when this brings her into conflict with nursing staff.

### **Attempts to Regain Control**

Participants attempt to mediate their perception of loss of control by focussing on small aspects of their environment which were controllable, for instance David talks about the significance of watching television:

you're no in control ay nothin ...at least if you can change the space and listen to something...even if it's just the news ... catch up ...even if it's just for five... ten minutes even if it's just background music it doesnae maiter. You need...need wee things like that ... they things mean more tae somebody who's been confined tae a room than anything. (David, 517-520)

For David, the ability to change channels on the television was an aspect of his experience that he was in control of. He could choose if and when he wanted to watch television and the content of what he watched. He is aware that this may seem insignificant to those around him as it appears to be such a small act, yet it is inherently meaningful within this extremely restricted environment.

By asking her mum to bring in cleaning products, Sarah felt able to control to a degree the risks she was facing and reduce her feeling of vulnerability.

but I think psychologically it was bugging me because I had an infection within the first few weeks that somebody had brought in to me ehm and I was doing everything. You know my mum came in with a bottle of flash because I became... I was so paranoid by that time about hygiene. (Sarah, 1103-1108)



## **Emotional Impact**

The experience of admission for transplantation was associated with a range of negative emotional experiences, including depression and anxiety. No participant described their experience as eliciting positive emotions. It seems that the psychological experience of isolation and severity of physical symptoms precipitates emotional distress. The following accounts from Robert and David highlight this:

I was low...as low as I probably have felt ever. Emh because I was just sitting speaking to [ ], it's a blur. I just broke down. I couldn't stop. It was just too much and that was probably half way through it, it was just too much to deal with. I couldn't deal with it...I was getting to the stage as I said if I hadn't had the palithernum drug (sighs) I don't how I would have coped with it. (Robert, 1272-1279)

I was very very weak ... I was so exhausted...tired. I wanted out...wanted home. That's the first thing...that's your goal ...that's your... ah I think if you can get home you'll pick up...but if you're in there ... I think depression starts to come ...ah really do...ah think you do. I don't know if it's depression mental wise. I just got depressed (David, 369-374)

Both Robert and David describe the experience in terms of feeling psychologically overwhelmed, leading to feelings of depression. Participants articulate feelings of low mood as related to the losses associated with the process, for example loss of control, loss of their home environment and family, loss of physical functioning and finally loss of their sense of self.

Participants also mentioned frequent periods of anxious or depressive rumination, particularly during times when they were unwell or alone. Rumination focussed on the risk posed to them by the transplant procedure, losses resultant from this and anxiety about whether the transplant would be successful. David describes this experience:

you're no ... thinking about other things...but if you've got time on your hands and you're feeling a wee bit ... reasonably well if you know what I mean in between you can ah think...think about the bad things...if you know what I mean there's too much time on your hands...too much...( David, 253-256)

Strategies utilised to cope with negative emotional experiences included distraction e.g. watching television, listening to music or reading books and magazines. Cognitive avoidance was also utilised as a way of coping, as Adam describes:



putting up a brave front, I think, ...Yeh...trying to skirt over some of the not so nice issues of treatment...or whatever, putting it to the back of you mind (Adam, 372-374)

This was not an unconscious defence or a process of denial but more an active strategy aimed at reducing the psychological impact of uncontrollable events.

In addition to the strategies mentioned, participants describe the emotional support provided by family and staff as being important in reducing the emotional impact of the transplant and thereby increasing their appraisals of coping. This is discussed in more detail under the super-ordinate theme of relationships.

### **Discussion: Psychological Experience of the Transplant Procedure**

Cognitive appraisal underpins participants' experience of transplant in the present study. Transplantation was perceived as a threatening procedure; with this appraisal commencing prior to their hospital admission for the procedure and being related to their knowledge and expectation of the procedure. Transplantation was consistently associated with negative emotional experiences such as anxiety and low mood, which were linked to the perceived threat and loss associated with this procedure. The experience of transplantation was believed to result in a number of losses, first and foremost a loss of perceived control, both over their environment and the self and, additionally, loss of physical functioning and loss of intimacy with family. Attempts at coping with the experience included positive reappraisal of the situation, seeking aspects of their environment that could be controlled, distraction, cognitive avoidance of distressing thoughts and utilising emotional support provided by others.

Although the present study is not an empirical validation of cognitive mediational models of coping with stress (e.g. Lazarus & Folkman, 1984; Folkman, 1997), the emergent themes of cognitive appraisal, perceived loss of control and emotional impact are consistent with the processes outlined by these theories. The themes describe the emotional experience of participants which reflects their appraisal of the situation as threatening, their perception of their available resources to deal with it and their attempts to cope.

Participants invariably described a primary appraisal of the procedure as a threat. Lazarus (1999) suggested that characteristics of a situation may increase the likelihood of such an appraisal, for example if a situation is unpredictable or undefined, of a lengthy duration, or occurs in the context of a number of other stressors. The process of transplantation is characterised by such factors. Hospital admission is lengthy and unpredictable, embedded in the context of risk to life both as a result of the transplant procedure and the cancer it is being used to treat. The potential threats associated with transplant are realistic and participants understanding of these is based on the risk communicated to them by their medical team at the point of deciding to undergo the procedure. This may be the point at which an appraisal of threat is made, shaping the experience of the whole procedure.

Certainly in the present study, it appears that the appraisals of the procedure were made by participants in advance of hospital admission, shaped by their knowledge of the potential side effects and risk involved. This may explain the high levels of anxiety and depression exhibited by transplant recipients prior to transplantation (Andrykowski & McQuellon, 1999; Leigh *et al.*, 1995; Syrjala *et al.*, 1993). It has been suggested that recipients may distort or avoid information received during discussions with medical staff about the mortality and morbidity involved in medical procedures (Berry, 2004). This may function as a means of reducing the level of risk appraised in undergoing the procedure, enabling the secondary appraisal that sufficient psychological resources are possessed to cope with the procedure. However, individuals may also appraise risks as being higher than the information presented, increasing their appraisal of perceived risk. Perceived loss of control is associated with clinically significant levels of distress across the transplant process (Fife *et al.*, 2000).

Strategies utilised were both cognitive and behavioural and could be described as emotion focussed and meaning based, reflecting Folkman's (1997) model of coping. For example, participants attempted to cognitively reframe their situation in an attempt to view it more positively; this is analogous to the process described by Folkman (1997) of positive reappraisal.

### **3.2.2.3. Theme 3 - Physical Side Effects**

#### **Description and Interpretation**

As participants described their experience of the transplant procedure, they frequently referred to physical side effects experienced as a consequence. In particular, problems with eating, fatigue and Hickman lines (a central venous catheter fitted to enable direct access for the administration of medication, it remains in situ for the duration of treatment). Physical side effects were associated with increased psychological distress.

### **a) Eating Problems**

Varying in severity and duration, nausea, vomiting and mucositis were associated with problems with eating for all participants post-transplant. For example:

there were certain things that after the high dose I couldn't eat because my mouth was really on high alert almost...every nerve ending or whatever, any hot food would be like 100% worse in your mouth...so there were only certain things you could eat. Am talking about spicy things...anything slightly spicy...even putting pepper on things...was driving you up the wall. Ughh...attacking your mouth. Em...so I started going off certain foods [ ]... ah just couldn't eat. Really I didn't like the food...it was bothering me I just wasn't able to eat it properly... plus I started having a lot of diarrhoea (Robert, 420-435)

I was struggling couldnae eat nothing... couldnae keep nothing doon ... was very nauseous. I wasnae bein sick I was just like wrenchin all night...it was dry. It was horrible ... it'd ay been better if you had been sick...if had there been something to be sick with but there wasnae (David, 172-175)

Participants described problems with eating as the most difficult side effect of the transplant to cope with during hospital admission, a side effect compounded by the perceived poor quality of the hospital food. Adam describes the strategy he utilised to cope with this:

'Food. I didn't like the hospital food. That was my biggest criticism. So...em... I had to rely on staff heating up soup or whatever that my wife had brought it and kinda ready meals which I was allowed so...food.' (Adam, 214-216)

By eating the food his wife brings in to the unit for him, Adam feels more in control of his eating. Other strategies used included eating small amounts frequently and sheer will power. Participants often faced the dilemma of not being able to leave the unit and go home until they began to eat, but could not or did not want to eat the hospital food, thereby increasing the duration of their stay. As Sarah discusses:

'I was determined that I was getting out that weekend and they were like you should stay here for another week...because you cannae eat anything and if you cannae eat anything you cannae take your tablets because I still was getting everything through a drip. And I was like well...give me a tin of mandarins (laughs). I sat and ate a tin a mandarins so that I could take my tablets...so I could get out of hospital. I had to prove that I could eat for a couple of days so that I could get out of hospital' (Sarah, 1381-1386)

For Sarah, the desire to leave hospital outweighed the potential risks of returning home when not physically ready. This motivated her to eat even though she did not want to as her ability to eat would indicate to the medical team that she is ready to go home.

## **b) Fatigue**

Extreme fatigue was a shared consequence of transplant. Developing post-transplant, this was debilitating and improved slowly in the months post-transplant. The fatigue was described as all-encompassing and long lasting, as exemplified by Robert:

ah was waking up in the morning and I was tired in the morning...ah was tired at night...ah was tired at night... ah was tired during the day... ah was falling asleep mid way through the day. Like today ah still feel tired at this time...ah still feel tired...its almost like my body has got into a routine of when ah was...when as was off and when ah was ill. (Robert, 654-670)

In listing his fatigue, Robert appears to be emphasising the unrelenting nature of this. It appears to be never ending. There is no point of the day where he does not feel exhausted. He remained tired a year following his transplant.

As depicted by Robert, the recovery of physical fitness and strength post-transplantation is slow. Participants described setting themselves small goals which acted as motivation to improve their fitness. Kate talks about her experience of trying to build up her strength gradually; she perceives the achievement of each small step as symbolic of her recovery.

bein able to walk down the street. Walk a wee bit further ...even just walking round the block ... just go for a walk...like getting a wee bit further round the block. Without feeling ... tired... things like that yeah.

Interviewer: so feeling that your strength's coming back?

yeah uh huh. Getting back to the gym ...been back to the fitness club and things like that (Kate, 550-552)

The trajectory of recovery is not smooth; as Kate goes on to explain:

it's like I was trying to do too much too soon ... but I never felt ...Id get a row from my mum...she'd tell me you've done too much today and I knew myself I had done too much. I did I had a few days where I did that and you suffered for it the next day...cause I couldn't move off the sofa the next day. But just being able to do these things that ...to me that was more important and I could put up with the being on the sofa for the next day ...if I felt I'd managed to something I couldn't have done the day before. (Kate, 570-576)

Kate is aware that she overstretched herself but simultaneously experiences a sense of achievement. This process of under activity and over activity is reminiscent of the experiences of those with chronic fatigue, reflecting a frustration with the functional limitations imposed by transplantation.

### **c) Hickman Lines**

Hickman lines were viewed by participants as a source of discomfort and anxiety. An illustration of this was provided by Jenny:

I got my Hickman line in just the week before so this was bothering us...because I had a big cut here where they put it in (groin)...ah dinnae ken why my cut was so big. I dinnae ken if they had problems but it swelled up so I had a lot of pain with that as well because when it came to that...I could hardly like sit on the toilet and that because it had swelled up (Jenny, 323-329)

Jenny appears to be trying to make sense of this; she is unsure why the cut was so big, why it has swollen. This emphasises that even in the absence of communication from medical staff, recipients will try to construct an understanding of their experience.

The perception of Hickman lines as a source of discomfort or anxiety seemed in some part to reflect the vulnerability participants experience, the line is a direct route from the external world which is full of potential threats to the internal world which is perceived as defenceless and exposed.

### **Discussion: Physical Side Effects**

A range of distressing physical side effects were experienced by participants post-transplantation, including problems relating to eating, fatigue and Hickman lines. Side



effects were experienced as psychologically distressing. In particular, not eating due to pain or nausea was viewed as a significant cause of distress. High levels of extreme fatigue were described which were chronic in duration, resulting in periods of frustration and disappointment at the lack of perceived progress towards recovery.

The association between physical side effects and psychological distress described by participants in the present study is in agreement with the finding of Molassiotis *et al.*, (1996), who demonstrated that transplant recipients find loss of appetite, nausea, vomiting and fatigue to be among the most distressing side effects of the transplant procedure. Furthermore, increased levels of perceived distress at physical symptoms were associated with higher levels of psychological distress, in particular anxiety and depression. Physical side effects, such as loss of appetite, and psychological distress, such as depression and anxiety have the potential to prolong hospital admission potentially further increasing distress (Preito *et al.*, 2002).

Recent studies highlight the longer term impact of reduced physical functioning in relation to psychological and social functioning post-transplantation (Andrykowski *et al.*, 2005; Byar *et al.*, 2005; Hjermstad *et al.*, 2004; Gruber *et al.*, 2003). Both the present study and existing research suggest that most transplant recipients experience significant physical side effects which are associated with psychological distress. Most recover from side effects over the course of the year following transplant, returning to work and social roles. However, compared to the general population, impairments in functioning remain even up to 5 years post-transplant. In particular, fatigue appears to become chronic and impairments in role functioning may remain (Hjermstad *et al.*, 2004).

Two controlled clinical trials evaluating the efficacy of psychological interventions to assist recipients to manage pain and nausea during transplantation have been reported (Syrjala *et al.*, 1992; Syrjala *et al.*, 1995). The results of these studies suggest that training in relaxation skills, imagery or self hypnosis prior to and during hospital admission were associated with reduced pain and nausea. Adding further cognitive behavioural components to treatment i.e distraction, identifying and challenging thoughts did not further enhance pain relief. This suggests that relaxation and imagery alone may be effective interventions for managing treatment related side effects during hospital admission potentially reducing distress and length of admission. No interventions appear to have been published in relation to improving fatigue or psychological distress post-transplant.

### **3.2.2.4. Theme 4- Relationships**

#### **Description and Interpretation**

Relationships with family and staff are key to participants' experience of the transplant process and coping with this. Participants distinguish between relationships with family and staff but both are viewed as sources of support helping participants to cope as well as being problematic, potential sources of stress. Additionally, participants expressed concern over the potential impact that the transplant process had had on close family members.

#### **a) Relationships with Friends and Family**

Family members (in particular spouses) were viewed by participants as providing emotional and practical support. This support seems to be instrumental to the process of coping with hospitalisation for the transplant and the protracted recovery. David's experience epitomises the accounts of participants:

it's the support that you get from your family and that it really does help...I feel sorry for anybody tryin to go through that without any family. It must be very...very hard. It must be for them...I can understand how people don't cope and that's why you need really good friends and family to support you and help you (David, 448-452)

The source of emotional strength for David was his family and friends. Accentuating the importance of support from family and friends, David reflects on how difficult the experience must be for those whose support is limited and empathises with them. He makes a direct link between lack of support and problems with coping. This is a position shared by other participants, for example Jenny:

Aye...because that's what I thought it must be really difficult for folk that's on their own. Ken that havenae got anybody or you get some folk like...ah know somebody that's husband just couldn't cope wae it ken and didnae gie her much help...whereas my hubby is the opposite he wouldnae let us dae anything (Jenny, 513-517)

At times however, relationships with family and friends were experienced as sources of stress or outlets for emotional distress, as the following account from Robert typifies:

I was snapping at the dogs...I was snapping at the kids...I was snapping at [name]...eh I actually snapped at a customer...which was very unprofessional. But he said something to me and I was like...whoof...straight back at him...which I would never do ehm and I had to get myself back out of it. (Robert, 727-731)

For Robert, the irritation and frustration he experiences in relationships reflects the emotional distress he was experiencing. These problems with relationships are alien to his sense of self, he is not normally like this and for him this was the prompt to seeking professional support from a clinical psychologist.

### **b) Relationships with Staff**

In addition to support from family, support provided by staff during hospital admission was an integral aspect of coping with the procedure. Information, practical advice and emotional support were provided by staff. Emotional support was valued over and above other forms of support as the following accounts from Robert and David highlight:

but when I wasn't well when I was going through a really like high temperature ...sitting on the edge of my bed at like 4 o'clock in the morning and the nurse sort of peeking in and noticing me and sitting down for half an hour and at least sitting speaking to you. Giving...its almost like giving their time to you and that's kind of what I think I was missing was that ... interaction. Human interaction that's it. (Robert, 1398-1404)

They will treat you as a human being. They treat you different... I'd... you know what I mean knew that you were suffering. They knew that you had your ups and your downs and gave us a smile on your face and it helps. No being sympathetic or ken what I mean...being...just being normal...ken trying to be natural about the whole thing...they know what you're going through... probably more than me. (David, 194-199)

For both Robert and David a key aspect of emotional support provided by staff is their perception that the medical staff value them as an individual, a human being who was suffering, not just an object to be fixed. Participants describe feeling valued and supported by the whole multi-disciplinary team providing their care across the whole process; from the ward auxiliary through to their consultant haematologist. For example, Robert talks about the value of support he received from clinical psychology in helping him to reengage with his life and deal with the psychological distress he experienced as a consequence of the transplant.

Ah actually think that she did a lot for me and ah think that a lot of it was[] being able to admit defeat in a way. That something had got to you... that you just got sit back now and ah think a lot of it was ... she was dead easy to speak to and am no very... I wouldn't open up to a lot... many people but ah think with this I have to. I've had to... I think that the idea that ... I'm going to see somebody...a psychologist...was like phff...yeah right whatever... its just not me. As I say I wouldn't say I was completely dismissive I was hoping that somebody might be able to help... but thinking to myself that I cant see this working... but I think that it was probably more apparent after the second or third time that I saw her that I was beginning to be a bit more relaxed about it. (Robert, 962-970)

In addition to experiencing relationships with staff as sources of emotional support, participants described some of their encounters with staff as frustrating and compounding their experience of loss of control and dependency. They experienced a conflict between their needs as human beings and the professional role of nursing staff to complete tasks.

That sort of got a bit of a battle of wills...against me and some of them... some of them would be like because you have to...which wasnae why. Fine I'll get out my bed if you have a valid reason and I think they just gave up about it at that point. Cos it was like... right she she's no getting up (laughs). But I would get up and have my shower and get my bed changed... it was no big deal...it was at the same time everyday...I didn't see what the problem was. But some of them came in sort of jobs worth.' (Sarah, 677-694)

For Sarah, the task orientated focus of some of the nursing staff is at times frustrating. It seems to represent a sense of being objectified, of losing meaning as an individual and becoming a task to be completed.

### **c) Impact on Family**

Invariably, participants expressed concern about the emotional impact of the transplant process on their close family members. They were concerned about the demands placed on them in providing support during the transplant procedure and in the period of recovery, yet they acknowledge that this support was essential. An example of this is provided by Adam, who describes his concerns about the impact on his wife:

It's been quite demanding probably emotionally on my wife you know

Interviewer: in what way?



ye...just the whole shock...of the whole episode...you know from the very first night when I collapsed in the house you know...it was...I think it's been quite a rough journey for her...over two years. You know there was times I was lying up there at night in ward [ ]...er...and just thinking is everything ok at the house...you know...but she seemed to get on fine...its just a bit of worry you know...that's all (Adam, 455-466)

For those participants undergoing allograft transplants, additional concern was expressed relating to the impact of cell donation on their sibling donor:

Ehm and I think that's what I got in my head that and I think sort of side effect wise that it can cause kidney problems for her in the long term... its just hopefully it wont but then you are sort of thinking she is doing this for me and im hoping that that's now not what cures me and gives her long term problems. (Sarah, 745-747)

I was concerned ... she had to go on the stem cell separator machine...and she also had to get like growth stimulating injections she had to get that. So I was a wee bit concerned about that cause that is not normal ...so ... I was a wee bit concerned for her (Kate, 375-378)

### **Discussion: Relationships**

Relationships were viewed as a source of emotional and practical support, instrumental to coping with the transplant experience. Whilst both practical and emotional support was received, participants emphasised the value of emotional social support, perceiving this as a representation of their value as individuals. However, relationships were also experienced as sources of stress, conflict occurring when other participants perceived that they were being objectified and not valued as an individual. At times conflict in relationships was viewed as a way of venting and communicating emotional distress to others. Participants describe a dilemma over the impact the experience may have on close family members. They are concerned that it may have a negative emotional impact but are dependent on this support for their own psychological wellbeing. For allograft transplant recipients there is the additional concern regarding the physical impact of donation on their donor.

These findings are in agreement with existing research relating to the role of social support and coping with cancer and in particular coping with SCT/BMT. Empirical studies indicate that family and social environment have an impact on psychological functioning of transplant recipients post-transplant (Bressi *et al.*, 1997; Colon *et al.*, 1991; Molassiotis *et al.*, 1997; Rodrigue *et al.*, 1999; Syrjala *et al.*, 1993). For example, Bressi *et al* (1997) found

that high levels of warmth and protective over-involvement from close family members was protective for transplant recipients who had lower levels of psychological distress. Qualitative research has found that transplant recipients perceive family and friendships as supportive and integral to their coping with the process and post-transplantation quality of life (Ferrell *et al.*, 1992; Holmes *et al.*, 1997).

Research also indicates that recipients' illness and the process of transplantation impacts on family, in particular carers (Boyle *et al.*, 2000; List *et al.*, 2001; McGrath *et al.*, 2006). List *et al.* (2001) found that caregivers report the same levels of psychological distress as transplant recipients prior to transplant and more impairment in family relationships. Carers provide emotional and physical care to transplant recipients post-transplantation; which occurs in the context of existing demands such as employment and their anxiety with regard to the uncertainty of the procedure and fears of disease recurrence. Although the demand placed on carers declines over time, they may still be providing care up to 6 years post-transplant so the emotional impact of the illness and transplant is enduring (Boyle *et al.*, 2000).

There is a dearth of literature examining the role and impact on health care professionals providing support for transplant recipients (Botti *et al.*, 2006). Botti *et al.*, (2006) suggest that this may negatively impact on the quality of life and psychological functioning of nursing staff. The study suggests that clinical supervision frameworks be implemented specifically to support nursing staff to provide psychosocial care. The findings of this study contrast with those of Molassiotis *et al.* (1997) who found low to moderate levels of stress and burnout among a sample of SCT/BMT transplant nurses. However they concluded that the impact on psychological functioning of staff was moderated by a psychosocial staff support programme provided in this service.



### **3.2.2.5. Theme 5 - Change of Meaning and Altered Perception of Self**

#### **Description and Interpretation**

The themes of change of meaning and perception of self are dominant in participants' accounts of their experience of the transplant process and their subsequent recovery.

#### **a) Change of Meaning**

The experience of transplant is something which participants appear to attempt to make sense of, to find meaning in their suffering. The majority of participants articulate beliefs that their transplant has positively altered the meaning of their life and the significance of life events. Descriptions are provided of feeling less bothered by daily hassles of life, an increased value of their own life and health, an increased value of relationships and a re-prioritisation of life goals. David provides a lucid account of this:

whether I'm first or last getting off the plane ...or in a plane or in a queue or in a bus getting on. I go on you go its no a problem ... its no. There's more to life than pissing about. It's the same ...you ken, money's no everythin ... ken .. your mair realise that your health's more important to you than anything ...and the people round about you (David, 445-447)

Robert's narrative contrasts to that of other participants in perception of change of meaning. He does not believe that the transplant has increased the positive meaning or value of his life:

I'm no one of these people that...my wife has changed her view on things. She kinda lives for today... ah don't...I'm just still the same as I was. I am exactly the same as I was before...I still think the same...I still act the same. Its just I carry around some baggage from the last 3 or 4 years...if I was...if this thing had happened to me in my 20's by the time I was in my 30's I would have forgotten about it. I think because it's happened now I will always remember it... partly because it was kinda traumatic as well. But I m not one of these people who has gone away and found god or...nut. (Robert, 1345 – 1352)

Although Robert emphasises that life has not changed meaning by repeating how he is the same person, there is a real sense throughout his account that the meaning of life has changed. He now perceives himself as psychologically vulnerable and he is trying to make sense of this change of meaning, reasoning that it is not a spiritual change but a reflection of the life stage at which his illness and transplant occurred.

### **b) Altered Perception of Self**

In addition to altering the meaning of life, participants talk about the transplant as altering their perception of themselves. Changes to perception of self are experienced both as positive and negative as illustrated by the following accounts from Robert and Sarah:

sometimes think to myself I am like a baby growing up again because they kind of wipe your immune system away from you. A lot of your life skills seem to be wiped out at the same time... ah... as well...ah mean like having to cope with things. Things that I had built up through experience all seemed to disappear overnight the same as the immune system and it's like trying to get it all back...So its just trying to get yourself back into life...into actual living...rather than being frightened of it...type of thing...know what I mean? It's just crazy.' (Robert, 1580-1589)

if anything else I am probably going to be more confident. Probably more sort of willing to try things...you know that's sort of why I booked my holiday and stuff because before it would have just been like I cannae do that and then like well...now I can and I will do it...I will give it a bash anyway. (Sarah 1335-1338)

The analogy Robert uses to describe his experience is that of a child having to relearn life skills. The experience of transplant has fundamentally altered his sense of himself as competent and confident. He feels deskilled and anxious as a consequence and seeks understanding by questioning the interviewer. In contrast, Sarah feels more confident. She feels that because she has coped well with this experience, she is resilient and able to cope with other things which previously caused her anxiety.

### **Discussion: Change of meaning and altered perception of self**

Participants describe the transplant experience as having altered the meaning of life for them and their self-perception. On the whole this was experienced as a positive shift in meaning symbolic of psychological and spiritual growth. However for one participant, there is a sense that the changes to meaning of life and perception of self are experienced as loss.

Both empirical and qualitative research with SCT and BMT recipients has explored the concept of meaning; the results of the present study are consistent with the findings of these studies. For example, Johnson-Vickberg *et al* (2001) established that higher ratings of global meaning are associated with reduced psychological distress and enhanced quality of life. However the cross-sectional and retrospective design of Johnson-Vickberg *et al*'s (2001) study means that it is not possible to determine whether higher ratings of global meaning signify a changed meaning resultant from transplantation or reflect stability in pre-transplant ratings of meaning. Additionally, the majority of qualitative studies evaluating the impact of SCT/BMT suggest that frequently recipients describe an enhanced sense of global meaning, in particular enhanced relationships, enhanced appreciation with life and increased spirituality (Ferrell *et al.*, 1992; Holmes *et al.*, 1997; Xuereb & Dunlop, 2003).

Supporting the association between meaning and psychological distress, perceiving transplantation as a stressful event negatively impacting on sense of self predicts depression and poor psychological adjustment during the transplant process (Bressi *et al.*, 1995).

The findings of the present study suggest that there may be some merit to theoretical and conceptual models of stress and coping and adjustment to cancer which advocates a key role for meaning and cognitive appraisal (e.g. Folkman, 1997; Park & Folkman, 1997; Moorey & Greer, 2002). However, whilst research suggests that the experience of psychological growth and enhanced global meaning may be an outcome of the transplant procedure, it is worth noting that the majority of studies with this population exclude those whose disease has relapsed. As such, enhanced global meaning may reflect the experiences for whom transplant has been successful and offered them a second chance at life.

#### **3.2.2.6. Theme 6 - Normality**

##### **Description and Interpretation**

Recurring throughout participants' accounts was a desire to be normal, to be back to their pre-illness self. They perceive the transplant process as offering them a route back to normality, to this old self, through returning to previously valued roles and activity. Accomplishing this represents coping with the transplant process and returning to this pre-illness self. Coping was therefore perceived as both a process and an outcome. Most

participants were still in the process of recovery and holding on to the belief that they will return to normality and their pre-illness self. Violations of this expectation of normality were linked with the experience of psychological distress.

#### **a) Desire for and Expectation of Normality**

The desire for a return to normality and pre-illness self is eloquently expressed by Adam:

Physical fitness...just trying to get back to where I'm happy...happy with...you know...and as I said I think I am there now...the work element...and really that's us I think...just trying to get some sort of normal family life back...(Adam, 452 -456).

For Adam, normality was tangible, symbolised by returning to personally meaningful roles. He sees this as the end point of the transplant process and believes that he has achieved this. Similarly for Kate, normality was desired and its achievement was reflected in concrete steps such as reduced frequency of follow-up appointments with the medical team. She believes that she has achieved normality by following their advice.

I was desperate to get my life back to normal and that...but I have stuck to what they said ...and I've done everything they told me to do I think that's probably how, why I feel better now ...but I don't think there's any one particular thing. I think just the wee steps like going from...From every day...to once a week to once a fortnight and then once a month. I think that's a sign once again about normality and control and everything as well (Kate, 600-605)

#### **b) Violation of Expectation of Normality**

Robert provides an example of the impact of the violation of the expectation of return to normality post-transplant:

aye its that...its that emh...expectation level of come on its 6 months now...some of you has got to be working right now and its not and that is a frustration in that because its not working right. Emh mentally...physically...physically your walking is still a struggle for me...standing is still a struggle...tiredness is still there...nothing seemed to be any different and your expectation levels are that you want just to get on with it...well mine was. Mine were and that's what I wanted...that's what I wanted to just get on and forget about it as much as possible...ehm and as I say it tripped me up completely by surprise' (Robert, 870-880)

He is shocked and surprised by his ongoing impairment and the disparity between this and his expectation of recovery from his transplant. There is a real sense in this account that transplantation was supposed to make him whole, normal again and it has failed to live up to this expectation. His disappointment is clear.

### **Discussion: Normality**

The desire to be normal and to reconnect with the perceived pre-illness self and associated activity is evident throughout the accounts. This is as an expectation widely held of the transplant procedure, that, if successful, it will facilitate a return to a normal life. Accomplishing re-engagement with valued roles and activity (e.g. physical activity and sport, socialising and employment) is perceived as signifying an end point of the process and symbolises successfully coping with the transplant procedure. However, violation in this desire or expectation of normality was associated with psychological distress, including low mood and anger.

Both empirical and qualitative research with this population has emphasised that recipients proceed to transplantation with the belief that they will return to normal post-transplant. Returning to normal post-transplantation is a desirable goal inherently linked to quality of life. Violation of this expectation is linked to poorer psychological adjustment (Andrykowski *et al.*, 1996; Andrykowski *et al.*, 2005; Ferrell *et al.*, 1992; Holmes *et al.*, 1997 and Xuereb & Dunlop, 2003). Up to 7 years post-transplantation transplant recipients display poorer health, physical functioning and psychological adjustment than a matched sample of healthy controls (Andrykowski *et al.*, 2005), suggesting that transplantation does not return recipients to full health or normality as defined by their pre illness levels of functioning. Paradoxically transplant recipients also describe greater psychological growth and enhanced spiritual meaning than healthy controls (Andrykowski *et al.*, 2005). The implication of this being that while transplantation recipients may not return to their pre-illness self, there is potential for them to find positive meaning and construction of a new self mitigating psychological distress. This is akin to Folkman's (1997) concept of meaning based coping.

Underpinning the theme of normality is the process of appraisal and construction of meaning, concepts inherent in models of coping with stress (Folkman, 1997; Lazarus & Folkman, 1984; Park & Folkman, 1997) and psychological adjustment to cancer (Moorey &



Greer, 2002). Normality is an idiosyncratic concept; individual appraisal determines the level of functioning symbolising normality, and there is potentially a difference between returning to their prior self and a level of functioning that would fall within normal range. Likewise the meaning of a violation of an expectation of returning normality is consequent on the interpretation the individual makes of this.

### **3.3. Summary of Findings**

The principal aim of the present study was to explore the experience of coping with SCT/BMT. In order to achieve this, a qualitative retrospective cross-sectional design was utilised. Semi-structured interviews were undertaken and analysis undertaken using Interpretative Phenomenological Analysis of interview material. Additionally, participants completed measures of psychological adjustment (HADS, MAC). These provide a description of the sample. What follows is a summary of the findings of the study.

Five out of the 6 participants completed both the HADS and the MAC. Two participants scored above the clinical cut off point on the anxiety subscale on the HADS with levels suggestive of borderline generalised anxiety. No participant scored above the clinical cut off point on the depression subscale of the HADS. No participant met the clinical case criteria on the MAC, suggesting that they had an adequate adjustment style and were coping with their cancer diagnosis.

Seven shared super-ordinate themes were identified, six of which were deemed to be of relevance to the research aims and analysed in further detail. These were: Existential issues; psychological experience of transplant procedure; physical side effects; relationships; change of meaning and perception of self and, finally, normality.

The theme of existential issues is characterised by fear of death, hope for survival and perceived risk. Fear of death, hope for survival and a second chance at life reflected simultaneous appraisals of the transplant process and were shaped by perception of risk. Participants' existential concerns influenced their appraisal of the procedure and consequently the process of coping.

The theme of psychological experience of transplant procedure incorporated cognitive appraisal of the procedure, loss of perceived control and emotional response. Interpretation

of this theme indicated that participants appraised the transplant procedure as a threat and perceived themselves to have lost control, both over their environment and their self. The appraisal of the transplant procedure as a threat and their perceived loss of control were related to rumination and negative emotional experiences such as anxiety and depression. They perceived that there was little that they could do to alter their situation and focused attempts at coping on small aspects of their environment that they could change, such as the television channel and reducing their emotional distress.

The theme of physical side effects related to the side effects experienced as a direct consequence of the conditioning and transplant process and included problems with eating, fatigue, problems with Hickman lines. The side effects described were acute; occurring during the hospital admission for transplantation and chronic, characteristic of recovery from transplantation. Physical side effects were generally associated by participants with psychological distress. Cognitive, behavioural and emotional strategies were utilised by participants in an attempt to cope with side effects. These strategies were aimed at reducing emotional distress and altering attributed meaning.

The theme of relationships encompassed relationships with family and friends and staff members. Relationships were experienced both as sources of support and as potential sources of stress. Emotional support provided by family and staff members was perceived as fundamental to coping with transplantation, both during the acute phase of hospital admission for the procedure and in the post discharge recovery. Additionally concerns about the potential impact of their illness and transplant on family members were identified.

The theme of change of meaning and altered perception of self encompasses changes to global meaning and sense of self. Largely participants described changes as being positive and resulting in enhanced meaning and value of life, relationships and self. However for one participant, changes to meaning of life and perception of self were experienced as negative and representing loss. Change to meaning and sense of self relates to cognitive reappraisal and reflects for participants an outcome of coping with their illness and the transplant procedure.

Finally, normality incorporates both desire and expectation of normality, as well as violation of expectation of normality. Participants invariably described an expectation that transplantation would be successful and would return them to normality, their pre-illness self

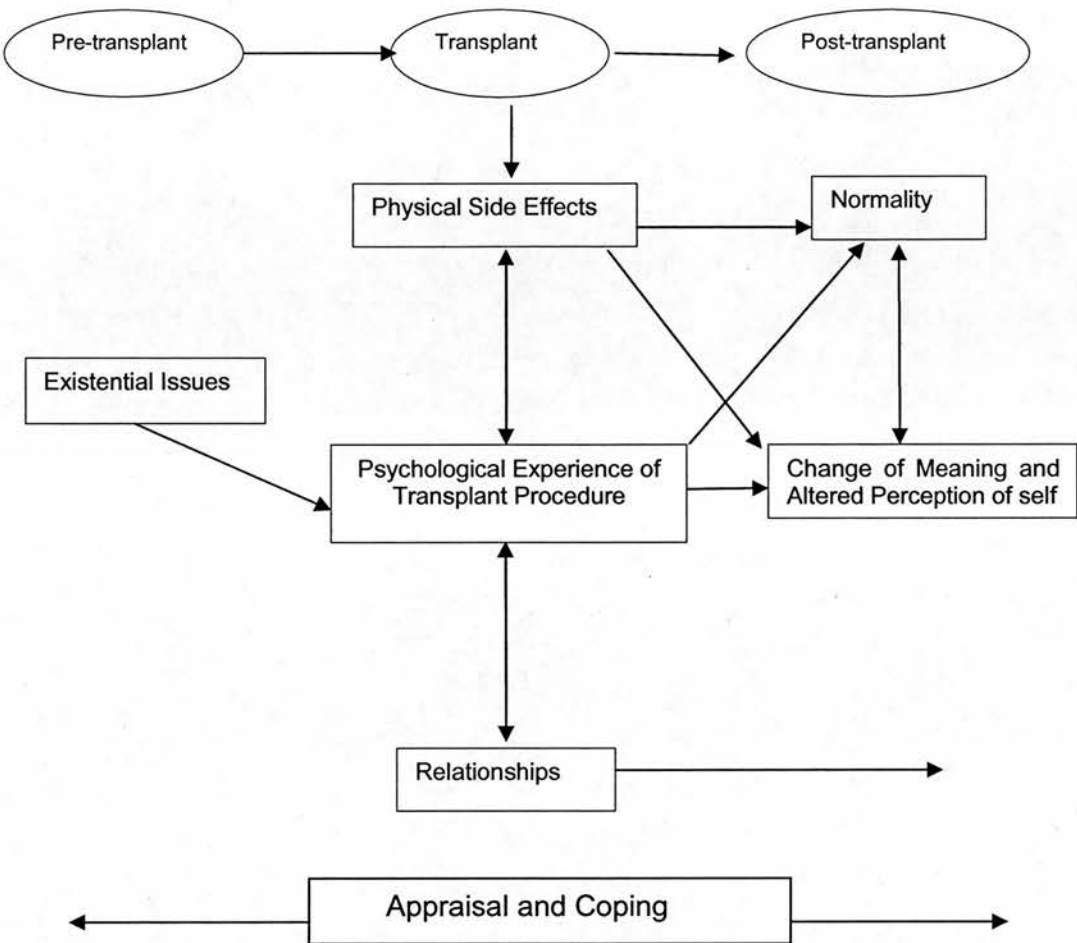
and their valued and meaningful roles. Most participants were still in the phase of recovery and retained this expectation. However, violations in this expectation such as continuing physical dysfunction and failure to return to normal, was associated with psychological distress. Of note, participants experience coping both as a process and an outcome.

### **3.4. Relationship between themes**

Although the 6 super-ordinate themes emerged from analysis as distinct conceptual components of participants' perceptions of coping with SCT/BMT, there is a degree of inter-relationship between these themes.

A chronological framework provides a context within which to embed themes. Given the retrospective nature of the present study, this relationship is speculative. Existential concerns such as fear of death, hope for survival and perceived risk are of particular relevance to the pre-transplant and transplantation phase of the process. They shape cognitive appraisal and emotional response thus influencing psychological experience of the procedure. The themes of physical side effects and relationships also impact on psychological experience of the procedure i.e influencing emotional response. This is bi-directional and psychological experience impacts on both perception of side effects and relationships. Both physical side effects and relationships can be seen to have an ongoing impact on participants' experience of coping with transplantation during the post-transplant recovery phase. The interrelationship between themes post-transplant phase is complex; psychological experience of the transplant procedure influences changes to meaning and perception of the self and normality. Change to meaning and perception of the self is also influenced by ongoing physical side effects and interacts with the desire or expectation of normality and violations of this expectation. Ongoing physical side effects also impact on normality. See Figure 4 for diagrammatic representation of relationship between themes.

Although not explicitly discussed as themes in the present study, underpinning all is the process of appraisal and coping, it is the idiosyncratic meaning attributed to events and the self which is related by participants to psychological distress and coping with this. For participants coping is conceptualised both as a process of managing the negative appraisal and impact of the transplant (incorporating cognitive and behavioural responses) and as an outcome, equivalent to psychological adjustment.



**Figure 4: Diagrammatic representation of relationship between themes**

## **4. PERSONAL REFLECTION**

A reflective diary was maintained throughout the course of the study, to enable reflexive awareness and to document potential influence on the research process (Elliot *et al.*, 1999; Malterund, 2001). The following section describes the potential impact of my role on the study and the emotional impact of the process, accompanied by related diary extracts.

### **4.1. Role**

My academic and clinical roles have influenced the research process in a number of ways. I am presently in my fourth and final year of training as a Clinical Psychologist on the Flexible training route, specialising in Oncology. Throughout the duration of the study I have had multiple roles, undertaking clinical placements, providing a service contribution to Oncology and undertaking academic assignments to meet requirements of doctoral training. Whilst all of these aspects have influenced the study in different ways, in particular balancing time demands during the course of the study; it is perhaps my work role which has had the greatest influence.

Over the three years I have been training and working in Oncology I have provided a psychological screening service to those undergoing SCT and BMT. This led to the selection of the topic of coping with transplant for the present research. During this time I have gained an in-depth knowledge of the challenges faced by patients undergoing this procedure and developed relationships with those providing support to them. Undoubtedly this has influenced how I have perceived participants and they have perceived me as a researcher. I think that my clinical role may have had both a beneficial and detrimental influence on the study.

For instance, I have had previous contact with a number of the participants within my clinical role and the others knew that I had worked closely with the haematology service providing their care. I suspect that this may have influenced how they perceived the study and their willingness to talk about particularly emotional or difficult experiences such as their fear of death.

I suspect that they came to me with a belief of a shared understanding, knowing that I knew what they had been through; I know what transplant involves and would perhaps understand. I am quite concerned that I do not exploit their experiences for my own personal or professional gain. I feel that I have an ongoing responsibility to these individuals and the team that provides their care.



I wonder if this feeling of responsibility is greater than if I had not worked in the service. (14.07.2007)

I was aware that whilst conducting the research I was not in my clinical role, however it was at times difficult not to step into this role. I had to remind myself that I was not assessing or treating these individuals and felt that there were times when my background knowledge and experience made me reluctant to explore particularly sensitive topics in more detail.

I think that I have been at times reluctant to open up topics that they have raised, due to my own concern that this may do more harm than good. I feel that I have an ongoing duty to these patients and hope that my research findings will have some practical utility to them. (13.06.2007)

It was hard not to reflect back on what individuals said in a way which would influence their perception of events and subsequent account as I might if working with them therapeutically. I suspect at times that how I reflected back did influence participants, for instance Kate uses the word control a lot during her interview, at one point I had reflected back to her that I wondered if what she was talking about was control. I wonder if she would have used this word as frequently in her account had I not mentioned this, yet reflecting back understanding of what participants had said was necessary to prompt further description or clarification from them.

My work role had direct impact on the study when I prioritised the clinical need of a potential participant, meeting them in my clinical role and thereby excluding them from the study and reducing the number of participants.

Issues relating to the influence of my role were discussed with academic and clinical supervisors of the study.

## **4.2. Emotional Impact**

Although I am familiar with many of the distressing issues described by participants and feel comfortable addressing these in clinical practice, the experience of undertaking research and listening to their accounts was still a sad experience at times. Perhaps this reflects the depth of engagement required by the qualitative analysis. Even so, my clinical role seems to have normalised my understanding of the issues faced by transplant recipients and has I think reduced the potentially negative emotional impact or distress that I may have felt if

undertaking this study without my clinical background. This was brought home to me during discussion with the psychologist who undertook thematic analysis on a sample of transcripts:

Discussed [name] with [name], she was talking about the impact of reading and interpreting this account. She told me she had had to stop and have a break half way as it was pretty heavy going emotionally, and wondered what it was like for me. I said that it was sad but I was okay with it. (09.07.2007)

The emotional impact of undertaking the research and the difference between this and clinical experience of working with this population was discussed during clinical supervision.

## **5. IMPLICATIONS AND EVALUATION**

The findings of the present study have both theoretical and clinical relevance. They are consistent with existing literature pertaining to the psychological impact of transplantation, coping with stress and psychological adjustment to cancer, suggesting that they have theoretical generalisability and transferability. What follows is a discussion of the theoretical, clinical and service implications of the study findings. Finally an evaluation of the limitations of the present study and methodological approach is considered.

### **5.1. Theoretical Implications**

The study supports the application of cognitive models of coping with stress to the experience of coping with transplantation. Appraisal of the procedure as life threatening and as uncontrollable influenced the coping responses and psychological experience of participants consistent with the models of Lazarus and Folkman (1984), Folkman (1997) and Moorey and Greer (2002). Cognitive and behavioural coping strategies were used by participants to reduce the emotional impact and alter situational meaning (e.g. positive reframing). These strategies are analogous to those proposed by Folkman (1997).

Transplantation impacted on global meaning (Park & Folkman, 1997) and altered perception of self, a finding consistent with empirical and qualitative research in this population (Andrykowski *et al.*, 2005; Ferrell *et al.*, 1992). These changes were related to appraisal and reappraisal, emotional response and the experience of coping with the transplant process. Again, this is consistent with cognitive models of coping with stress and cancer, particularly Folkman (1997) and Moorey and Greer (2002). Change to meaning was associated with both positive and negative psychological adjustment.

This would suggest that clinical interventions which enhance coping may have a positive impact on psychological adjustment in this population. However, there is a distinct lack of research applying and evaluating the efficacy of psychological interventions in this population. Two studies have been published which demonstrate the efficacy of relaxation and imagery training in reducing pain and nausea experienced during transplantation (Syrjala *et al.*, 1992; Syrjala *et al.*, 1995). No studies appear to have been reported which address other aspects of psychological adjustment pre, during or post-transplantation. Given the high

levels of psychological distress and ongoing impact on functioning demonstrated by transplant recipients it would appear that such research is desperately needed.

The present study found that existential issues (Yalom, 1980; Frankl, 1959/2004) such as the fear of death and hope for survival influenced recipients' perceptions of the procedure, and their emotional responses. No studies have been published which explicitly investigate this issue in this population. Again, this would indicate that this topic requires investigation. Perhaps high levels of perceived threat to survival and to self may explain the high levels of distress apparent prior to transplantation (Fife *et al.*, 2000). However, as indicated this is an area which requires further investigation.

Emphasis was placed on the value of social support provided by family, friends and staff in helping participants to cope with the transplant process. Again, this finding is consistent with the existing literature base (e.g. Bressi *et al.*, 1997). Research indicates that this may have a negative psychological impact on carers (e.g. List *et al.*, 1991); however the issue remains relatively unexplored. Similarly, research exploring the impact of this on psychological functioning of staff is limited. Given the importance of emotional support to transplant recipients, increased understanding of the psychological impact of providing emotional support on carers and health care staff may be important.

Whilst the present study has focused on the experience of SCT/BMT transplant recipients, it would be interesting to compare the experiences of this group with other cancer or chronic illness groups e.g. solid organ transplants as there may be aspects of such experiences which are generalisable not just condition specific.

## **5.2. Clinical Implications**

Whilst acknowledging the limitations of evidence base and design of the present study. The study findings suggest that utilising psychological interventions based on cognitive models of coping with stress and psychological adjustment to cancer may help individuals to cope with the transplant process.

For example, Folkman and Greer (2000) suggest an intervention aimed at promoting psychological wellbeing in those with serious illness based on Folkman's (1997) model of coping with stress. This focuses on situational beliefs about personal control, and meaning

based coping strategies as aspects of the coping process which are amenable to change and associated with enhanced psychological wellbeing. This intervention includes:

- Creating conditions for the appraisal of challenge as opposed to threat by finding out what is meaningful to the patient and establishing meaningful, attainable goals.
- Emphasising opportunities for personal control e.g. identifying small meaningful goals
- Encouraging behaviour to achieve goals
- Maintenance of positive mood, for example by eliciting accounts of previous pleasant life events and encouraging activities that provide a sense of achievement and enjoyment.

In relation to the experience of coping with transplantation as presented in this study, this intervention would seem to be of utility. For instance, communicating level of risk in terms of probabilities rather than percentages may potentially reduce recipients' perception of threat and enhance the potential for transplant to be viewed as a challenge. Enhancing perceived control by providing increased opportunity for recipients to control small aspects of their environment (e.g. bringing in suitable food from home to be heated up in the unit or encouraging recipients to undertake activities of daily living when physically able) could also be beneficial. Interventions could be used to increase perceived control over physical side effects (e.g. by providing training in relaxation and imagery prior to transplant, Syrjala *et al.*, 1992; Syrjala *et al.*, 1995). Finally, maintenance and encouragement of positive emotional experiences could be facilitated by encouraging transplant recipients to bring into hospital objects or activities that they find enjoyable (e.g. computers and books), or personally meaningful (e.g. photographs).

The present study also highlights the value of emotional support in enhancing transplant recipients' ability to cope. Given the potential impact that the provision of such support may have on families and health care staff it may be useful to consider the provision of psychological support to these groups. Such support may reduce the potential for negative psychological impact enabling maintenance of their supportive role. For example, provision of supervision to nursing staff. It also suggests that increased support from healthcare



professionals may be beneficial to those who do not perceive that they have sufficient support from friends and family.

### **5.3. Implications for Participating Service**

The result of the present study and evidence considered so far suggests that the application of psychological interventions based on cognitive models of coping may have clinical utility in this population. Given the lack of empirical research the application of such interventions would need to be applied cautiously and rigorously evaluated.

This points to an increased role for clinical psychology with this population, in terms of developing, applying and evaluating psychological interventions for transplant recipients and their families and providing support and supervision to staff involved in the role of supporting transplant recipients. A role which is in keeping with NICE guidelines (2003) and recommendations regarding the future role of clinical psychologists in Scotland; a recent report by the Chief Medical Officer recommended that the role of psychologists should focus on 'leading the development of services, training and supervising others, acting as consultants and using their research skills to innovate and evaluate new approaches' (CMO, 2005, p2).

For instance, thorough psychological assessment could be undertaken at routine outpatient clinic prior to admission for transplantation, and brief interventions to assist recipients to develop strategies to cope with the transplant. Provision of ongoing psychological support during the transplant procedure should be provided. It may be of utility to introduce psychological assessment of recipients at transplant follow-up clinics, providing a means of normalising psychological distress and enabling problems with psychological adjustment to be identified and treated before they have a chronic impact on functioning.

### **5.4. Limitations of Present Study**

The following section outlines and discusses potential limitations of the present study. These relate to homogeneity of sample, the characteristics of the sample in relation to time since transplant and disease status and issues relating to the study design.

The present sample was not fully homogenous, in that two participants had undergone allograft transplant. Empirical research is at present equivocal as to whether type of transplant has an impact on psychological adjustment (Leigh *et al.*, 1995), and the analysis undertaken did not suggest that transplant type impacted on outcome on measures of psychological adjustment or in terms of the super-ordinate themes. Perhaps the present study provides an indication of factors pertinent to transplant recipients in general; something that may have salience to clinical practise, and conceptual understanding.

It is interesting to note that whilst those invited to participate had undergone transplantation between 2005 and 2006, all participants had undergone transplant in 2006. This raises a question as to why this might be the case. A number of reasons for this could be speculated, for instance, transplant survivors who have had a longer period of recovery may feel that they have adjusted to the process and do not wish to discuss it or perhaps those who remain distressed are those least likely to opt into a study. The fact that the present sample appear to be coping successfully with their diagnosis of cancer suggests that those who don't, may not volunteer to participate in such studies. Existing research suggests that many of those successfully treated by transplantation experience ongoing psychological distress (Neizert *et al.*, 1998), indicating that the present sample may be biased towards those who successfully cope with the procedure.

Additionally, this group were currently disease free; the study is therefore limited to those without active disease post transplantation. Research into the experience of those for whom transplant is not successful or whose disease has relapsed is needed. No studies were identified which have examined the psychological experience of this subgroup, yet these may be a group who experience the most psychological distress. Perhaps the reason such research has not been undertaken relates to ethical considerations, yet this leaves the question as to which position is least ethical; to research the experience of this group or to ignore their experience due to problems with research design and concerns about obtaining ethical approval.

Finally, the retrospective nature of the study means that it is not possible to definitively argue that participants' accounts reflect the reality of their experience at the time of the transplant. The process of recollection may be biased or participants may not have recalled important aspects of the process. A prospective longitudinal study with repeated measures taken at different points in the transplant process would provide empirical evidence of the

link between coping strategies and psychological adjustment. However, Folkman and Moskowitz (2004) suggest that there is 'no gold standard' (p748) by which coping can be measured. Measuring coping in 'real time' (p749) is useful for identifying specific thoughts and strategies and directly associating these with psychological adjustment, but it may not fully reflect the complexity of the process and potentially can:

'miss the broader conceptualisations of coping that are better perceived with the benefit of some retrospection, such as those that involve finding meaning' (P749)

Folkman and Moskowitz (2004) conclude that both approaches to research and measurement of coping are valid. In particular they highlight the utility of retrospective narrative research when attempting to understand the phenomenon of coping as it enables aspects of coping not addressed by measures to be identified, this information can subsequently be used to develop or adjust measurement tools.

In sum, this suggests that whilst it is important to acknowledge the potential limitations of the present study, the use of IPA in attempting to understand the phenomenon of coping with transplantation was an appropriate methodological approach providing relevant theoretical and clinical implications.

## **5.5. Methodological Evaluation**

The interpretative procedure of IPA is an active process shaped by the researcher (Malterud, 2001; Braun & Clarke, 2006). Although themes are discussed as emergent from the data, this occurs only through the process of identification and interpretation on the part of the researcher. It is not claimed that the interpretation presented is the only possible or valid interpretation of participants' accounts.

As IPA relies on participants being able to verbalise their experience to the researcher, it is dependent upon expressive language skill and the assumption that what is communicated reflects the intended meaning. The method is therefore limited to those who are able to articulate their emotional experience (Willig, 2001), perhaps excluding those who have limited expressive language skill, for instance those with learning disability or cognitive impairment. However, this may also depend on the skill of the researcher to elicit rich and vivid description of experiences. Clinical psychologists are skilled in eliciting accounts about

thoughts and emotions from individuals across the life span including those who have limited expressive language capabilities.

A further limitation of this approach relates to the time consuming nature of data collection and analysis, an interview lasting an hour may take 10 hours to transcribe and a further 24 to analyse. It is not therefore an approach that would have utility if one sought to evaluate the experience of a large number of individuals in a short period of time, or as a means of auditing outcome for services, such research would better be conducted using a quantitative or positivist methodological approach.

However, IPA (Smith, 1996) is an appropriate method for the study of subjective experience and was therefore an appropriate method for the aims of the present research study. Stevens (1996) suggests that:

the nature of such experience makes it difficult to apply the usual procedures of natural science, for to study subjective experience is to concern yourself with *meanings* (i.e. beliefs, feelings, ways of making sense and evaluating the world as perceived). Such a subject matter is essentially qualitative not quantitative: for while we may be able to describe our subjective experience we cannot measure it, at least not without losing its richness and authentic feel. (p150)

The importance of taking this approach to an exploratory study of the subjective experience of transplant recipients is perhaps best demonstrated by the existential issues raised by participants in the present study. Fear of death and changes to meaning and altered sense of self were important aspects of the process to participants, yet these may have been easily overlooked by a quantitative study based on preconceived ideas about the experience. Indeed, the identification of fear of death as influencing the experience of transplantation, which although it seems almost obvious, appears to be an area unconsidered by previous research in this population.

## **6. CONCLUSION**

The present study aimed to provide an exploration of the subjective experience of SCT and BMT recipients in relation to coping with the transplantation using a qualitative research design and analysis (IPA, Smith, 1996). Additionally, the study sought to contextualise participants' accounts by providing a description of current emotional functioning using the Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983) and the Mental Adjustment to Cancer Scale (Watson *et al.*, 1988). Furthermore the study aimed to relate emergent themes to existing literature on the psychological impact of transplantation and coping with stress and cancer.

The study identified 6 shared emergent themes related to the research question: existential issues, psychological impact of the transplant procedure, physical side effects, relationships, change of meaning and altered perception of self and finally normality. These findings were consistent with previous research undertaken in this population and suggest that cognitive models of coping with stress and cancer potential utility in understanding the experience of coping with transplantation. Potential areas for future research (e.g. death and dying), clinical implications and potential service implications are discussed. To conclude, the aims and objectives of the present study were successfully achieved using the methodological approach of IPA (Smith, 1996).



## References

- Alby, N. (1991). *Leukaemia: Bone marrow transplantation* BPS Books, Cambridge, England.
- Andersen, B. L., Golden-Kreutz, D. M., & DiLillo, V. (2001). Cancer. In Baum A, Revenson TA, Singer JE (Ed.), *Handbook of Health Psychology* (pp. 709-727) Lawrence Erlbaum Associates, London.
- Andrykowski, M. A., & McQuellon, R. P. (1999). Psychological issues in hematopoietic cell transplantation. In E. Donnall-Thomas, K. G. Blume & S. J. Forman (Eds.), *Hematopoietic cell transplantation* (Second ed., pp. 398-406). Oxford: Blackwell.
- Andrykowski, M. A., Bishop, M. M., Hahn, E. A., Cella, D. F., Beaumont, J. L., Brady, M. J., et al. (2005). Long-term health-related quality of life, growth, and spiritual well-being after hematopoietic stem-cell transplantation. *J Clin Oncol*, 23(3), 599-608.
- Andrykowski, M. A., Brady, M. J., Greiner, C. B., Altmaier, E. M., Burish, T. G., Antin, J. H., et al. (1995). 'Returning to normal' following bone marrow transplantation: Outcomes, expectations and informed consent. *Bone Marrow Transplantation*, 15, 573-581.

- Andrykowski, M., Brady, M., & Henslee-Downey, P. (1994). Psychosocial factors predictive of survival after allogeneic bone marrow transplantation for leukemia. *Psychosomatic Medicine*, 56(5), 432-439.
- Arora, N. K., Finney Rutten, L. J., Gustafson, D. H., Moser, R., & Hawkins, R. P. (2007). Perceived helpfulness and impact of social support provided by family, friends, and health care providers to women newly diagnosed with breast cancer. *Psycho-oncology*, 16(5), 474-486.
- Ashby-Wills, T., & Filer-Fegan, M. (2001). Social network and social support. In A. Baum, T. A. Revenson & J. E. Singer (Eds.), *Handbook of health psychology* (pp. 209-234). New Jersey: Lawrence Erlbaum Associates.
- Barracough, J. (2000). *Cancer and emotion: A practical guide to psycho-oncology* (3rd ed.). Chichester: Wiley.
- Beck, A. T., Rush, A. J., Shaw, B. F., & Emery, G. (1979). *Cognitive therapy of depression*. New York: Guilford Press.
- Berry, D. (2004). *Risk, communication and health psychology*. Maidenhead: Open University Press.
- Bishop, M. M., Rodrigue, J. R., & Wingard, J. R. (2002). Mismanaging the gift of life: Noncompliance in the context of adult stem cell transplantation. *Bone marrow transplantation*, 29(11), 876.

- Bonnet, D., & Dick, J. E. (1997). Human acute myeloid leukemia is organised as a hierarchy that originates from a primitive hematopoietic stem cell. *Nature Medicine*, (3), 730-737.
- Botti, M., Endacott, R., Watts, R., Cairns, J., Lewis, K., & Kenny, L. (2006). Barriers in providing psychosocial support for patients with cancer. *Cancer Nursing*, 29(4), 309-316.
- Boyle, D., Blodgett, L., Gnesdiloff, S., White, J., Bamford, A. M., Sheridan, M., et al. (2000). Caregiver quality of life after autologous bone marrow transplantation. *Cancer Nurs*, 23(3), 193-203; quiz 204-5.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.
- Brenner, M. K., Rill, D. R., Moen, R. C., Krance, R. A., Miro JR, J., Anderson, W. F., et al. (1993). Gene-marking to trace origin of relapse after autologous bone marrow transplantation. *Lancet*, 341(8837), 85-86.
- Bressi, C., Guggeri, G., Capra, E., Brambilla, V., Guidotti, B., Parma, L., et al. (1997). Integrated psychological intervention in the cancer patient and his family. *New Trends in Experimental & Clinical Psychiatry*, 13(1), 71-78.
- British Psychological Society. (2004). Good practice guidelines for the conduct of psychological research within the NHS.

- British Psychological Society. (2006). *Code of ethics and conduct*. Leicester: The British Psychological Society.
- British Society for Blood and Marrow Transplantation. (2007). *UK transplant activity*. Retrieved 02/04/2007, from [www.bsbmt.org/www/activity.html](http://www.bsbmt.org/www/activity.html)
- Byar, K. L., Ellers, J. E., & Nuss, S. L. (2005). Quality of life 5 or more years post autologous hemopoietic stem cell transplant. *Cancer Nursing*, 28(2), 148-157.
- Campbell, K. (2005). *Bone marrow and stem cell transplantation (BMT)*. London: Leukaemia Research.
- Cannon, W. B. (1914). The interrelations of emotions as suggested by recent physiological researches. *American Journal of Physiology*, 25, 256-282.
- Cassel, J. (1976). The contribution of the social environment to host resistance. *American Journal of Epidemiology*, 104, 107-123.
- Chief Medical Officer. (2005). *The Role of the Applied Psychologist In A Modernised Scottish Health Service: Report by the psychology advisory group to the chief medical officer*
- Colon, E. A., & Callies, A L Popkin, M K McGlave,P.B. (1991). Depressed mood and other variables related to bone marrow transplantation survival in acute leukemia. *Psychosomatics*. 32(4):420-5, 1991.,

- Copelan, E. A. (2006). Hematopoietic stem-cell transplantation. *New England Journal of Medicine*, 354(17), 1813-1826.
- Cramer, P. (2000). Defense mechanisms in psychology today: Further processes for adaptation. *American Psychologist*, , 637-646.
- Crawford, J. R., Henry, J. D., Crombie, C., Taylor, E. P. (2001) Brief Report: Normative data for the HADS from a large non-clinical sample. *British Journal of Clinical Psychology*, 40, 429-434
- Dallos, R., & Vetere, A. (2005). *Researching psychotherapy and counselling*. Maidenhead, England: Open University Press.
- Davies, D., & Bhugra, D. (2004). *Models of psychopathology*. Maidenhead: Open University Press.
- Deeg, H. J., & Socie, G. (1998). Malignancies after hematopoietic stem cell transplantation: Many questions, some answers. *Blood*, 91(6), 1833-1844.
- Deeg, H. J., Flourmoy, N., Sullivan, K. M., Sheehan, K., Buckner, C. D., Sanders, J. E., et al. (1984). Cataracts after total body irradiation and marrow transplantation: A sparing effect of dose fractionation. *International Journal of Radiation Oncology, Biology, Physics*, 10(7), 957-964.



- DeLeve, L. D., Shulman, H. M., & MacDonald, G. B. (2002). Toxic injury to the hepatic sinusoids: Sinusoidal obstruction syndrome (veno-occlusive disease). *Seminars in Liver Disease, 22*, 27-42.
- Dougall, A. L., & Baum, A. (2001). Stress, health and illness. In A. Baum, T. A. Revenson & J. E. Singer (Eds.), *Handbook of health psychology* (pp. 321-338). New Jersey: Lawrence Erlbaum Associates.
- Duncombe, A. (2002). ABC of clinical haematology. In D. Provan (Ed.), (Second ed., ). London: BMJ Books.
- Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology, (38)*, 215-229.
- Fawzy, F. I., Cousins, N. W., Kemeny, M. E., Elashoff, R., & Morton, D. (1990). A structured psychiatric intervention for cancer patients: 1. changes over time in methods of coping and affective disturbance. *Cancer Intervention, 47*, 720-725.
- Fawzy, I., Fawzy, N., Hyun, C. S., Elashoff, R., Guthrie, D., Fahey, J. L., et al. (1993). Malignant melanoma: Effects of an early structured psychiatric intervention, coping, and affective state on recurrence and survival 6 years later. *Archives of General Psychiatry, 50(9)*, 681-689.

- Ferrell, B., Schmidt, G. M., Rhiner, M., Whitehead, C., Fonbuena, P., & Forman, S. J. (1992). The meaning and quality of life for bone marrow transplant survivors. Part 1: the impact of bone marrow transplant on quality of life. *Cancer Nursing*, 15(3), 153-160.
- Flowers, M. E. D., Parker, P. M., Johnston, L. J., Matos, A. V. B., Storer, B., Bensinger, W. I., et al. (2002). Comparison of chronic graft-versus-host disease after transplantation of peripheral blood stem cells versus bone marrow in allogeneic recipients: Long-term follow-up of a randomized trial. *Blood*, 100(2), 415-419.
- Folkman, S. (1997). Positive psychological states and coping with severe stress. *Social science & medicine*, 45(8), 1207-1221.
- Folkman, S., & Greer, S. (2000). Promoting psychological well-being in the face of serious illness: When theory, research and practice inform each other. *Psycho-oncology*, 9(1), 11-19.
- Folkman, S., & Moskowitz, J. T. (2004). Coping: Pitfalls and promise. *Annual Review of Psychology*, 55 Feb, 745-774.
- Frankl, V. E. (1959/2004). *Man's search for meaning*. London: Rider.
- Freud, S. (1884/1989). Neurosis of defense. In P. Gay (Ed.), *The freud reader* (). New York: Norton and Company.

- Futterman, A. D., Wellisch, D. K., Bond, G., & Carr, C. R. (1991). The psychosocial levels system. A new rating scale to identify and assess emotional difficulties during bone marrow transplantation. *Psychosomatics*, 32(2):177-86, 1991.,
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine.
- Grassi, L., Rosti, G., Albertazzi, L., & Marangolo, M. (1996). Depressive symptoms in autologous bone marrow transplant (AMBT) patients with cancer: An exploratory study. *Psycho-Oncology*, 5(4), 305-310.
- Greer, S., & Watson, M. (1987) Mental Adjustment to Cancer: its measurement and prognostic importance. *Cancer Survey*, 6, 439-453
- Gruber, U., Fegg, M., Buchmann, M., Kolb, H. J., & Hiddemann, W. (2003). The long-term psychosocial effects of haematopoietic stem cell transplantation. *Eur J Cancer Care (Engl)*, 12(3), 249-56.
- Hjermstad, M. J., Knobel, H., Brinch, L., Fayers, P. M., Loge, J. H., Holte, H., et al. (2004). A prospective study of health-related quality of life, fatigue, anxiety and depression 3-5 years after stem cell transplantation. *Bone marrow transplantation*, 34(3), 257-266.
- Holmes, S., Coyle, A., & Thomson, E. (1997). Quality of life in survivors of bone marrow transplant. *Journal of Cancer Nursing*, 1(3), 106-116.

- Holmes, T. H., & Rahe, R. H. (1967). The social readjustment rating scale. *Journal of Psychosomatic Research*, 11, 213-218.
- Janoff-Bulman, R. (1992). *Shattered assumptions: Towards a new psychology of trauma*. New York: Free Press.
- Johnson-Vickberg, S. M., Duhamel, K. N., Smith, M. Y., Manne, S. L., Winkel, G., Papadopoulos, E. B., et al. (2001). Global meaning and psychological adjustment among survivors of bone marrow transplant. *Psycho-Oncology*, 10(1):29-39, 2001 Jan-Feb.,
- Kelly, D., Ross, S., Gray, B., & Smith, P. (2000). Death, dying and emotional labour: Problematic dimensions of the transplant nursing role? *Journal of Advanced Nursing*, 32(4), 952-960.
- Kolb, E. A. (2006). Hematopoietic stem cell transplant. *Medicine*, 03/04/2007 from [www.emedicine.com](http://www.emedicine.com)
- Lazarus, R. S. (1966). *Psychological stress and the coping process*. New York: McGraw-Hill.
- Lazarus, R. S. (Ed.). (1990). *Stress, coping and illness*. New York: Wiley.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer.

- Lee, S. J. (2005). New approaches for preventing and treating chronic graft-versus-host disease. *Blood*, 105(11), 4200-4205.
- Lee, S. J., Loberiza, F. R., Antin, J. H., Kirkpatrick, T., Prokop, L., Alyea, E. P., et al. (2005). Routine screening for psychosocial distress following hematopoietic stem cell transplantation. *Bone Marrow Transplant*, 35(1), 77-83.
- Leigh, S., Wilson, K. C., Burns, R., & Clark, R. E. (1995). Psychosocial morbidity in bone marrow transplant recipients: A prospective study. *Bone Marrow Transplantation*. 16(5):635-40, 1995 Nov.,
- List, M. A., Daugherty, C. K., Banik, D. M., Menke, C., Cornetta, K., & Larson, R. A. (2001). Psychosocial adjustment of patients and caregivers prior to allogeneic bone marrow transplantation. *Bone Marrow Transplantation*, 27(11), 1181-8.
- Loberiza, F. R., Jr., Rizzo, J. D., Bredeson, C. N., Antin, J. H., Weeks, J. C., & Lee, S. J. (2002). Association of depressive syndrome and early deaths among patients after stem-cell transplantation for malignant diseases. *Journal of Clinical Oncology*, 20(8), 2118-2126.
- Loberiza, F. R., Jr., Zhang, M. J., Lee, S. J., Klein, J. P., LeMaistre, C. F., Serna, D. S., et al. (2005). Association of transplant center and physician factors on mortality after hematopoietic stem cell transplantation in the united states. *Blood*, 105(7), 2979-87.



- Loberiza, F. R., Rizzo, J. D., Bredeson, C. N., Antin, J. H., Horowitz, M. M., Weeks, J. C., et al. (2002). Association of depressive syndrome and early deaths among patients after stem cell transplantation for malignant diseases. *Journal of Clinical Oncology*, 20(8), 2118-2126.
- Malterund, K. (2001). Qualitative research: Standards, challenges and guidelines. *The Lancet*, 358, 483-488.
- McGrath, C., Montgomery, K., White, K., & Kerridge, I. H. (2006). A narrative account of the impact of positive thinking on discussions about death and dying. *Support Care Cancer*, 14, 1246-1251.
- McGrath, C., Montgomery, K., White, K., & Kerridge, I. H. (2006). A narrative account of the impact of positive thinking on discussions about death and dying. *Support Care Cancer*, 14, 1246-1251.
- McKay, P. J., Murphy, J. A., Cameron, S., Burnett, A. K., Campbell, M., Tansey, P., et al. (1996). Iron overload and liver dysfunction after allogenic or autologous bone marrow transplantation. *Bone Marrow Transplantation*, 17(1), 63-66.
- Molassiotis, A. (1997). A conceptual model of adaptation to illness and quality of life for cancer patients treated with bone marrow transplants. *Journal of Advanced Nursing*, 26(3):572-9, 1997 Sep.,

- Molassiotis, A., & Haberman, M. (1996). Evaluation of burnout and job satisfaction in marrow transplant nurses. *Cancer nursing*, 19(5), 360-367.
- Molassiotis, A., & Morris, P. J. (1997). Suicide and suicidal ideation after marrow transplantation. *Bone marrow transplantation*, 19(1), 87.
- Molassiotis, A., Van Den Akker, O. B. A., & Boughton, B. J. (1997). Perceived social support, family environment and psychosocial recovery in bone marrow transplant long-term survivors. *Social science & medicine*, 44(3), 317-325.
- Molassiotis, A., Van den Akker, O. B. A., Milligan, D. W., Goldman, J. M., & Boughton, B. J. (1996). Psychological adaptation and symptom distress in bone marrow transplant recipients. *Psycho-Oncology*, 5(1), 9-22.
- Moorey, S., & Greer, S. (2002). *Cognitive behaviour therapy for people with cancer* (2nd ed.). Oxford: Oxford University Press.
- Moorey, S., Greer, S., Watson, M., Gorman, C., Rowden, L., Tunmore, R., et al. (1991). The factor structure and factor stability of the hospital anxiety and depression scale in patients with cancer. *British Journal of Psychiatry*, 158, 255-259.
- National Institute of Clinical Excellence,. (2003). *Improving outcomes in haematological cancers : The manual* National Institute of Clinical Excellence.

NCCN. (2005). *Guidelines for distress management* National Comprehensive Cancer Network.

Neitzert, S., Ritvo, P., Dancey, J., Weiser, K., Murray, C., & Avery, J. (1998). The psychosocial impact of bone marrow transplantation: A review of the literature. *Bone Marrow Transplantation*, 22, 409-422.

Nordin, K., Berglund, G., Terje, I., Glimelius, B., (1999) The Mental Adjustment to Cancer Scale-a psychometric analysis and the concept of coping. *Psycho-oncology*, 8, 250-289

Osawa, M., Hanada, K., Hamada, H., & Nakauchi, H. (1996). Long term lymphohematopoietic reconstitution by a single CD34-low/negative hematopoietic stem cell. *Science*, (273), 242-245.

Park, C. L., & Folkman, S. (1997). Meaning in the context of stress and coping. article. *Review of General Psychology*, 1(2), 115-144.

Pearman, T. P. (1998). Mortality and morbidity following bone marrow transplantation: Predictive utility of psychological variables. *Dissertation Abstracts International: Section B: The Sciences & Engineering*, 58(7-B), 3932.

Potter, J., & Wetherell, M. (1987). *Discourse and social psychology: Beyond attitudes and behaviour*. London: Sage.

Prieto, J. M., Blanch, J., Atala, J., Carreras, E., Rovira, M., Cirera, E., et al. (2002).

Psychiatric morbidity and impact on hospital length of stay among hematologic cancer patients receiving stem-cell transplantation. *Journal of Clinical Oncology*, 20(7), 1907-1917.

QSR. (2002). *NVivo 2.0*. Doncaster, Australia: QSR International Pty. Ltd.

Rahe, R. H., Meyer, M., Smith, M., Kjaer, G., & Holmes, T. H. (1964). Social stress and illness onset. *Journal of Psychosomatic Research*, 8, 35-44.

Reid, K., Flowers, P., & Larkin, M. (2005). Exploring lived experience. *The Psychologist*, 18(1), 21-23.

Rodrigue, J. R., Pearman, T. P., & Moreb, J. (1999). Morbidity and mortality following bone marrow transplantation: Predictive utility of pre-BMT affective functioning, compliance, and social support stability. *International Journal of Behavioral Medicine*, 6(3), 241-254.

Schimmer, A. D., Minden, M. D., & Keating, A. (2000). Osteoporosis after blood and marrow transplantation: Clinical aspects. *Biology of Blood and Marrow Transplantation*, 6(2, Supplement 1), 175-181.

Schulz-Kindermann, F., Hennings, U Ramm, G Zander,AR, & Hasenbring, M. (2002). The role of biomedical and psychosocial factors for the prediction of

pain and distress in patients undergoing high-dose therapy and BMT/PBSCT.

*Bone Marrow Transplant. 2002 Feb;29(4):341-51,*

Scott, E. (2005). *Evaluation of a psychological screening service provided prior to haematopoietic stem cell and bone marrow transplantation in south east scotland*. Unpublished manuscript.

Seyle, H. (1936). A syndrome produced by diverse nocuous agents. *Nature*, 138, 32.

Smith, J. A. (1995). Semi-structured interviewing and qualitative analysis. In J. A. Smith, R. Harre & L. Van Langenhove (Eds.), *Rethinking methods in psychology* (pp. 9-26). London: Sage.

Smith, J. A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology and Health*, 11, 261-271.

Smith, J. A., Jarman, M., & Osborn, M. (1999). Doing interpretative phenomenological analysis. In M. Murray, & K. Chamberlain (Eds.), *Qualitative health psychology: Theories and methods* (pp. 218-240). London: Sage Publications.

Snaith, R. P., & Zigmond, A. S. (1994) *HADS: Hospital Anxiety and Depression Scale*. Windsor: NFER Nelson.



- Socie, G. (2006). Predicting secondary malignancies after allogeneic transplantation?  
*Blood*, 107(8), 3022-3023.
- Socie, G., Salooja, N., Cohen, A., Rovelli, A., Carreras, E., Locasciulli, A., et al.  
(2003). Nonmalignant late effects after allogeneic stem cell transplantation.  
*Blood*, 101(9), 3373-3385.
- Somerfield, M. R., & McCrae, R. R. (2000). Stress and coping research:  
Methodological challenges, theoretical advances and, and clinical applications.  
*American Psychologist*, 55(6), 620-625.
- Stanton, A. L., Collins, C. A., & Sworowski, L. (2001). Adjustment to chronic  
illness: Theory and research. In Baum A, Revenson TA, Singer JE (Ed.),  
*Handbook of Health Psychology* (pp. 387-405). New Jersey: Lawrence Erlbaum  
Associates.
- Stevens, R. (1996). The reflexive self: An experiential perspective. In R. Stevens  
(Ed.), *Understanding the self* (pp. 147-219). London: Sage.
- Sullivan, K., Deeg, H., Sanders, J., Klosterman, A., Amos, D., Shulman, H., et al.  
(1986). Hyperacute graft-v-host disease in patients not given  
immunosuppression after allogeneic marrow transplantation. *Blood*, 67(4),  
1172-1175.

Syrjala, K. L., Chapko, M. K., Vitaliano, P. P., Cummings, C., & Sullivan, K. M.

(1993). Recovery after allogenic marrow transplantation: Prospective study of predictors of long-term physical and psychological functioning. *Bone Marrow Transplantation*, 11, 319-327.

Syrjala, K. L., Cummings, C., & Donaldson, G. W. (1992/2). Hypnosis or cognitive behavioral training for the reduction of pain and nausea during cancer treatment: A controlled clinical trial. *Pain*, 48(2), 137-146.

Syrjala, K. L., Donaldson, G. W., Davis, M. W., Kippes, M. E., & Carr, J. E.

(1995/11). Relaxation and imagery and cognitive-behavioral training reduce pain during cancer treatment: A controlled clinical trial. *Pain*, 63(2), 189-198.

Taylor, S. (2001). Evaluating and applying discourse analytical research. In M. Wetherell, S. Taylor & S. J. Yates (Eds.), *Discourse as data: A guide for analysis* (pp. 311-331). London: Sage.

Thoits, P. A. (1986). Social support as coping assistance. *Journal of Consulting and Clinical Psychology*, 54, 416-423.

Trask, P. C., Paterson, A., Riba, M., Brines, B., Griffith, K., Parker, P., et al. (2002). Assessment of psychological distress in prospective bone marrow transplant patients. *Bone Marrow Transplantation*, 29, 917-925.

Watson, M., Greer, S., Young, J., Inayat, G., Burgess, C., & Robertson, B. (1988).

Development of a questionnaire measurement of adjustment to cancer: The MAC scale. *Psychological Medicine*, 18, 203-209.

Watson, M., Greer, S., & Bliss, J. M. (1989). *Mental adjustment to cancer (MAC) scale. user's manual*. Surrey: CRC Psychological Medicine Research Group.

Weinman, J., Wright, S., & Johnston, M. (Eds.). (1995). *Measures in health psychology: A user's portfolio*. London: NFER-Nelson.

White, C. (2001). *Cognitive behaviour therapy for chronic medical problems: A guide to assessment and treatment in practice*. Chichester: Wiley.

Widows, M. R., Jacobsen, P. B., & Fields, K. K. (2000). Relation of psychological vulnerability factors to posttraumatic stress disorder symptomology in bone marrow transplant recipients. *Psychosomatic Medicine*, 62, 873-882.

Williams, P., Barclay, L., & Schmied, V. (2004). Defining social support in context: A necessary step in improving research, intervention, and practice. *Qualitative Health Research*, 14(7), 942-960.

Williams, R. B., Barefoot, J. C., Califf, R. M., Haney, T. L., Saunders, W. B., Pryor, D. B., et al. (1992). Prognostic importance of social resources among patients with CAD. *Journal of the American Medical Association*, 267, 520-524.

Willig, C. (2001). *Introducing qualitative research in psychology: Adventures in theory and method*. Maidenhead: Open University Press.

Xuereb, M. C., & Dunlop, R. (2003). The experience of leukaemia and bone marrow transplant: Searching for meaning and agency. *Psycho-oncology*, 12, 397-409.

Yalom, I. D. (1980). *Existential Psychotherapy*. Basic Books.

Zabora, J., Brintzenhofesoc, K., Curbow, B., Hooker, C., & Piantadosi, S. (2001). The prevalence of psychological distress by cancer site. *Psycho-oncology*, 10, 19-28.

Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandanavia*, 67, 361-370.

**Participant Information Sheet**

**Research Project:**

***Coping with Stem Cell Transplant: the experience of patients***

**Researcher:** Eileen Scott, Trainee Clinical Psychologist, Clinical Psychology Services to Oncology [REDACTED]

You are being invited to take part in this research study being undertaken by the Department of Clinical Psychology at the University of Edinburgh. This is being carried out as part of the researcher's training in Clinical Psychology. Before you decide whether or not you would like to take part, it is important that you understand why the research is being carried out and what is involved in taking part.

***Please take time to read this information and feel free to ask any questions or clarify anything you are unsure about. Take some time to decide if you would like to take part.***

**Part 1: The Purpose of the Research and What Will Happen If You Take Part**

**What is the purpose of the study?**

The study is investigating the experience of undergoing stem cell or bone marrow transplant. At present our understanding of what undergoing a transplant is like is limited, however past research has found that people sometimes find it difficult to cope with their illness and treatment. It is hoped that by gaining a better understanding of patient's experience of coping with transplant we can improve the psychological care of transplant patients.

**Why have I been asked to take part?**

A number of patients who have undergone a stem cell transplant since January 2005 will be asked if they would like to take part in this study. It is hoped that between 10 and 15 transplant patients will agree to take part. You are being asked to take part because you have recently had a transplant and the medical team who you currently see in relation to your illness and transplant are aware that this research is being carried out.

**Do I have to take part?**

No – it is up to you to decide whether you would like to take part. If you do agree, you will be asked to sign a consent form. However, you are free to withdraw at any point without giving a reason. Deciding not to take part or withdrawing at any point after you have agreed to take part will not impact at all on the standard of care you receive.



### **What will happen to me if I agree to take part?**

You will be asked to take part in one interview asking about your experience of your illness and the transplant process.

It is expected that this interview will last for a maximum of an hour. The interview will be recorded and analysed to see if there are similarities between the ways that different transplant patients cope with their experience of illness and transplant.

At your interview you will also be asked to complete two questionnaires, these will ask about how your mood has been and how you cope with your illness. It is anticipated that these questionnaires will take a maximum of 30 minutes to complete.

In total it is expected that the meeting will last about an hour and a half. It is up to you whether you meet with the researcher at your home or when you are attending hospital for a clinic appointment.

### **Part 2: More Information on How the Research Will Be Conducted**

#### **What if I become upset during the interview or the study shows I am having difficulties?**

Psychological support is part of the routine care transplant patients receive; this will be available to you before, during and after the interview. Should you wish, the researcher will arrange an appointment for you with a clinical psychologist in the hospital and contact your consultant to let them know how you are feeling.

#### **What are the possible disadvantages/risks of taking part?**

As the research is asking about your experiences, it is unlikely that there will be any significant disadvantage to you.

#### **What are the possible benefits of taking part?**

We cannot promise that this study will help you, but the information you provide may help improve the psychological care of people undergoing stem cell or bone marrow transplants.

#### **Will my taking part in the study be kept confidential?**

The researcher will write to your G.P and Hospital Consultant to let them know that you are participating in the study but the information you give is confidential. Information containing your personal details will not be stored with your interviews or questionnaires. Access to this material will be limited to the researcher and supervisors of the research.

#### **What will happen to the results of the study?**

Once the report has been written up, the results will be presented to your medical team. A brief summary of the main findings will be available from the researcher if you would like to find out more about the outcome.

**What if there is a problem or I would like some independent advice?**

If you have any complaints about the way you have been dealt with during the study or would like some independent advice about participating in this research, please contact:

[REDACTED]

**Who can I contact if I would like more information?**

If you have questions or would like to discuss the research further, please feel free to contact me, Eileen Scott or my supervisor, [REDACTED]

*Many thanks for taking time to read this information sheet.*

Eileen Scott, Trainee Clinical Psychologist

NHS Headed Paper

**CONSENT FORM: Version 1 September 2006****Research Project:*****Coping with Stem Cell Transplant: the experience of patients*****Researcher:** Eileen Scott, Trainee Clinical Psychologist, Clinical Psychology Services to Oncology, [REDACTED]

<b>CONSENT REQUIRED</b>		<b>Please Tick</b>
1. I confirm that I have read and understood the information sheet dated .....(version .....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.		
2. I understand that my participation is voluntary and that I am free to withdraw my contribution at any time, without giving reason, without my medical care or legal rights being affected.		
3. I understand that the interviews will be audio-taped and that verbatim quotes may be used in the research report and subsequent publications.		
4. I understand that relevant sections of data collected during the study may be looked at by responsible individuals from the University of Edinburgh or from [REDACTED] (academic and clinical supervisors of the study). I give permission for these individuals to access my contribution.		
5. I agree to my G.P and Hospital Consultant being informed of my participation in the study		
6. I agree to take part in the above study		

**Name of patient****Date****Signature****Researcher****Date****Signature**

NHS Board

29 January 2007

Ms Eileen Scott

Dear Ms Scott

Full title of study: Coping and Psychological Adjustment: the experience of haematopoietic stem cell transplant patients across the transplant process

REC reference number: 06/81101/49

Thank you for your letter of 03 January 2007 responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered at the meeting of the Sub-Committee of the REC.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Application	5.1	31 December 2006
Application	1	10 October 2006
Investigator CV	1	04 October 2006
Protocol	version 1	01 September 2006
Covering Letter		31 December 2006
Covering Letter	1	10 October 2006
Letter from Sponsor	1	27 September 2006
Interview Schedules/Topic Guides	1	
Questionnaire: Hospital Anxiet & Depression Scale	1	10 October 2006
Letter of invitation to participants	1	31 December 2006
GP/Consultant Information Sheets		31 December 2006
Participant Information Sheet	2	31 December 2006
Participant Information Sheet: PIS	version1	01 September 2006

06/S1101/49

Participant Consent Form: Consent Form	1	01 September 2006
Response to Request for Further Information		03 January 2007
Supervisor CV	1	10 October 2006

**R&D approval**

The study should not commence at any NHS site until the local Principal Investigator has obtained final approval from the R&D office for the relevant NHS care organisation.

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**106/51101/49****Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project


Yours sincerely

  
Chair

Enclosures:

*Standard approval conditions*  
*Site approval form*

Copy to:

NHS  Research & Development Group



**NHS Board**

28 March 2007

Ms Eileen Scott



**Research Ethics Committee 01**

Dear Ms Scott

**Study title:** Coping and Psychological Adjustment: the experience of haematopoietic stem cell transplant patients across the transplant process

**REC reference:** 06/51101/49

**Amendment number:** 15 February 2007

**Amendment date:**

The above amendment was reviewed at the meeting of the Sub-Committee of the REC.

#### **Ethical opinion**

The members of the Committee present gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

#### **Approved documents**

The documents reviewed and approved at the meeting were:

Document	V	Date
Protocol	2	15 February 2007
Participant Information Sheet	3	15 February 2007
Notice of Substantial Amendment (non-CTIMPs)	1	15 February 2007
Covering Letter	1	15 February 2007

#### **R&D approval**

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

#### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**Committee Co-ordinator**



INVESTOR IN PEOPLE





### Appendix 3: Ethics Committee and Research & Development Approval

responsibilities within the Research Governance Framework for Health and Community Care, an extract of which is attached to this letter.

Yours sincerely

  
**R&D Director**

Enc      Research Governance Certificate  
            NRR authorisation  
            Tissue Policy (if applicable)  
            MT A (if applicable)

To be signed and returned  
fo be signed and returned  
(to be signed and returned by the recipient)

[REDACTED]

HAC/JK/ App-LRECamend/Scott

Ms Eileen Scott

[REDACTED]

[REDACTED]

RESEARCH &  
DEVELOPMENT  
OFFICE

[REDACTED]

Dear Ms Scott

LREC No:  
R&D Project ID No:  
Title of Research:

*Amendment:* 06/51101/49

I am writing in reply to recent correspondence in relation to the following amendment(s) to the above project.

20071W/P5Y/0

2

Coping and Psychological Adjustment: The experience of haematopoietic stem cell transplant patients across the transplant process.

No 1, dated February 2007

- *Data collection will be reduced to one interview and completion of measures. It is anticipated that total participation time for each participant would be reduced from 3 hours to 1 hour and 30 minutes.*
- *The sample population will be extended from those who are currently proceeding to transplant to those who have undergone a transplant since January 2005.*
- *Updated Patient Information Sheet, version 3 dated February 2007.*
- *Updated Research Study Proposal, version 2 dated February 2007.*

We have now received a copy of the amendment(s) and assessed any consequential changes in Division resource use. I confirm that Division management approval is extended to cover the specific changes intimated. You should be aware that approval for this amendment must also be received from [REDACTED] Research Ethics Committee before it is implemented

Yours sincerely

# Hospital Anxiety and Depression Scale

**nferNelson**  
understanding potential

Name ..... Date .....

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings she or he will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Ignore the numbers printed on the left of the questionnaire. Read each item and **underline** the reply which comes closest to how you have been feeling in the past week.

Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought-out response.

f  
o  
l  
d  
a  
l  
o  
n  
g  
d  
a  
s  
h  
e  
d  
l  
i  
n  
e

**I feel tense or 'wound up':**

- A Most of the time
- 3 A lot of the time
- 2 From time to time, occasionally
- 1 Not at all
- 0

**I still enjoy the things I used to enjoy:**

- D Definitely as much
- 0 Not quite so much
- 1 Only a little
- 2 Hardly at all
- 3

**I get a sort of frightened feeling as if something awful is about to happen:**

- A Very definitely and quite badly
- 3 Yes, but not too badly
- 2 A little, but it doesn't worry me
- 1 Not at all
- 0

(continued overleaf)



## Appendix 4: Hospital Anxiety and Depression Scale

### HOSPITAL ANXIETY AND DEPRESSION SCALE

D	<b>I can laugh and see the funny side of things:</b>
0	
1	As much as I always could
2	Not quite so much now
3	Definitely not so much now
	Not at all
A	
3	<b>Worrying thoughts go through my mind:</b>
2	
1	A great deal of the time
0	A lot of the time
	From time to time but not too often
D	Only occasionally
0	<b>I feel cheerful:</b>
1	Not at all
2	Not often
3	Sometimes
A	Most of the time
3	<b>I can sit at ease and feel relaxed:</b>
2	Definitely
1	Usually
0	Not often
D	Not at all
0	<b>I feel as if I am slowed down:</b>
1	Nearly all the time
2	Very often
3	Sometimes
	Not at all
A	
0	<b>I get a sort of frightened feeling like 'butterflies' in the stomach:</b>
1	Not at all
2	Occasionally
3	Quite often
	Very often

(continued overleaf)

Appendix 4: Hospital Anxiety and Depression Scale

HOSPITAL ANXIETY AND DEPRESSION SCALE

D  
0  
1  
2  
3

**I have lost interest in my appearance:**

Definitely

I don't take as much care as I should I may not take quite as much care

I take just as much care as ever

A  
3  
2  
1  
0

**I feel restless as if I have to be on the move:**

Very much indeed Quite a lot

Not very much Not at all

D  
0  
1  
2  
3

**I look forward with enjoyment to things:**

As much as ever I did

Rather less than I used to Definitely less than I used to Hardly at all

D  
0  
1  
2  
3

**I get sudden feelings of panic:**

Very often indeed Quite often

Not very often Not at all

A  
3  
2  
1  
0

**I can enjoy a good book or radio or TV programme:**

Often

Sometimes

Not often

Very seldom

D  
0  
1  
2  
3

**Now check that you have answered all the questions**

For office use only:

D: ☐ Borderline 8- 10

A: ☐ Borderline 8-10

D      A

© Zigmond and Snaith, 1983. From 'The Hospital Anxiety and Depression Scale,' *Acta Psychiatrica Scandinavica* 67, 361-70. Reproduced by kind permission of Munksgaard International Publishers Ltd, Copenhagen.

This measure is part of *Measures in Health Psychology: A User's Portfolio*, written and compiled by Professor Mane Johnston, Dr Stephen Wright and Professor John Weinman. Once the invoice has been paid, it may be photocopied for use within the purchasing institution only. Published by nferNelson Publishing Company Ltd, The Chiswick Centre, 414 Chiswick High Road, London W4 5TF, UK.

# MENTAL ADJUSTMENT TO CANCER SCALE (MAC)

Name: .....

Date: ..... Record Number: .....

**INSTRUCTIONS:** A number of statements are given below which describe people's reactions to having cancer. Please circle the appropriate number to the right of each statement, indicating how far it applies to you at present. For example, if the statement definitely does **not** apply to you, then you should circle 1 in the first column.

	<i>Definitely does not apply to me</i>	<i>Does not apply to me</i>	<i>Applies to me</i>	<i>Definitely applies to me</i>
1. I have been doing things that I believe will improve my health e.g. changed my diet.	1	2	3	4
2. I feel I can't do anything to cheer myself up.	1	2	3	4
3. I feel that problems with my health prevent me from planning ahead.	1	2	3	4
4. I believe that my positive attitude will benefit my health.	1	2	3	4
5. I don't dwell on my illness.	1	2	3	4
6. I firmly believe that I will get better.	1	2	3	4
7. I feel that nothing I can do will make a difference.	1	2	3	4
8. I've left it all to my doctors.	1	2	3	4
9. I feel that life is hopeless.	1	2	3	4
10. I have been doing things that I believe will improve my health e.g. exercising.	1	2	3	4
11. Since my cancer diagnosis, I now realize how precious life is and I'm making the most of it.	1	2	3	4
12. I've put myself in the hands of God.	1	2	3	4
13. I have plans for the future e.g. holiday, jobs, housing.	1	2	3	4
14. I worry about the cancer returning or getting worse.	1	2	3	4
15. I've had a good life; what's left is a bonus.	1	2	3	4
16 .. I think my state of mind can make a lot of difference to my health.	1	2	3	4
17. I feel that there is nothing I can do to help myself.	1	2	3	4

## Appendix 5 : Mental Adjustment to Cancer Scale (MAC)

	<i>Definitely does <b>not</b> apply to me</i>	<i>Does <b>not</b> apply to me</i>	<i>Applies to me</i>	<i>Definitely applies to me</i>
18. I try to carry on my life as I've always done.				
19. I would like to make a contact with others in the same boat.	1	2	3	4
	1	2	3	4
20. I am determined to put it all behind me.				
21. I have difficulty in believing that this happened to me.	1	2	3	4
	1	2	3	4
22. I suffer great anxiety about it.				
23. I am not very hopeful about the future.	1	2	3	4
24. At the moment I take one day at a time.	1	2	3	4
25. I feel like giving up.	1	2	3	4
26. I try to keep a sense of humour about it.	1	2	3	4
27. Other people worry about me more than I do.	1	2	3	4
28. I think of other people who are worse off.	1	2	3	4
	1	2	3	4
29. I am trying to get as much information as I can about cancer.				
	1	2	3	4
30. I feel that I can't control what is happening.				
	1	2	3	4
31. I try to keep a very positive attitude.				
	1	2	3	4
32. I keep quite busy, so I don't have time to think about it.				
	1	2	3	4
33. I avoid finding out more about it.				
34. I see my illness as a challenge.	1	2	3	4
	1	2	3	4
35. I feel fatalistic about it.				
	1	2	3	4
36. I feel completely at a loss about what to do.				
37. I feel very angry about what has happened to me.	1	2	3	4
	1	2	3	4
38. I don't really believe I had cancer.				
39. I count my blessings.	1	2	3	4
	1	2	3	4
40. I try to fight the illness.				
	1	2	3	4

Thank you for taking the trouble to complete this scale!

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## INTERVIEW SCHEDULE

### *General Questions about transplant and coping*

Please, tell me a bit about your cancer diagnosis and treatment?

Can you tell me about your transplant and your stay in hospital? – what happened?

Did this reflect their expectation?

How did they cope with it? Hospital admission, discharge home

What things have helped them to cope?

What kind of a person would you describe yourself as?

Can you describe what coping with your illness and treatment means to you?

What has been the most difficult aspect to date? How did you cope with that?

Do you have any particular ways of coping?

What things have they done to help themselves?

Can they describe other things or people who have helped?

Can you tell me a bit about how life has been since your discharge?

What if any, have been the long term impacts? Do they still experience anything which they believe is related to the transplant?

What impact has the transplant had?

Has your experience of transplant changed anything?

How do they feel about the experience?

Looking back how would they describe the experience of having a transplant?

What does having had a transplant mean to them now?



Thematic Coding	Interview Participant 1 : Robert	Exploratory Codes
		Coding:  <u>underlined</u> = description and content <i>Italic text</i> = language use <b>Bold text</b> = conceptual/interrogative
	P1: Ehm in 2005 right I decided that right im going to go for an operation.	<u>Describes start of process- deciding to have surgery</u>
	I: uh huh	
Control Cancer as alien	P1: so Id rather that its out than in. so went for that and was off id say until march and went back to work and by the June or July sort of stage. I finished work because the boss has said look too much stress and took me off the job. I started working from home and then in the august they noticed that its two dots had appeared in my left [REDACTED]. One in the middle and one in the side and they were very similar to what was on this [REDACTED], so they thought right cannae get a proper biopsy on this [REDACTED], lets go straight in and take it fresh from the left. So in the august I went in	<u>Wants the tumour removed; following this, returns to work, describes leaving work due to ill health. . his decision to have surgery</u>
		<u>Desire to have tumour removed to not seen as part of self.</u>
Stress		<u>Gives an account of time: time important</u>
		<u>Things were stressful because of his health; had to give up work; impact of illness</u>
Time period		<u>Shift in use or language to they from I</u>
		<u>Working from home</u>
		<u>Recurrence of the disease: this</u>
		<u>Leads to another biopsy: they can't do it on first lung but similarity? Indication that it's not?</u>
Loss of control over body		<u>Cant get biopsy on because of treatment</u>
		<u>Again mentions time: 5 months after first surgery</u>
		<u>Why the shift from his decisions to theirs? Does this signify his feeling of loss of control?</u>

# Appendix 7: Sample of Transcription and Coding

	and I got opened up on the left hand side, they took their biopsy and I think it was by the September, October mibbae I was getting treated for Hodgkin's. So ...	<u>Opened up:</u> there is something harsh about the phrase 'opened up' – why not surgery etc? Brutal  <u>Took their biopsy; belonging to them not him?</u>  <u>Diagnosis: one month after 2<sup>nd</sup> dots</u>  <u>Diagnosis=Hodgkin's disease</u>
	I: what did you think at the time, because I guess there was lots of uncertainty?	<u>Expressing anger, about diagnosis/ misdiagnosis. Trying to make sense of it 'the funny, one of the etc'</u>  Diagnosis as an emotional event, link between the two.
Anger  Lack of knowledge   Emotional impact of diagnosis	P1: I was angry, I was angry and mean that admittedly, the funny, one of the funniest things about it, you never quite appreciate things that are going on. Is that, it was ***** that told me I had Hodgkin's disease, so to be told that you've got cancer again is a real sickener.	Repetition emphasising anger (I was angry, I was angry), hesitant repetitions (the funny, one of the funniest) what was funny? Implies humour or in this situation strangeness?  <u>Lack power, understanding. Reflecting back on own knowledge with hindsight. : 'you never quite appreciate'. In relation to medical symptoms.</u>  <u>Experience of being diagnosed second time, overwhelmed with thinking about cancer.</u>  Sickener, sense of immediate negative impact. Not only is it cancer but you have it again. ? Significance of relapse? Impact on meaning of disease?  <u>Saying that what goes through your mind is whether you are going to die.</u>
	I: I can imagine	Repetition, hesitancy (ah, ah) sighs? Exhaustion/sadness?
Excessive thinking  Existential fear  Loss of future self  Loss of individuality	P1: because, ah, (sighs ) ah mean a lot of things go through your mind like em, you don't want to be another statistic where folk have fought for years and know what ah mean and never beaten. Ah mean, Ah	Lot of things go through your mind: out of control? Negative things, links to death. Example of famous person's daughter. Automatic link between cancer and death? Own mortality. Social comparison, link to others experience... Cancer is something to be fought like a battle? Enough strength to fight and win?  Media representations of cancer.  <u>Statistic: loss of sense of self as individual. Now a number, a disease?</u>

	think at that time ah cant remember who it was ah think it was Gloria Hunniford's daughter,	<u>Someone else with cancer dies so you make the link to your own situation. Fighting cancer for so long. Time frame again important. Start comparing self to others you have known or heard of with cancer. Shock at diagnosis, thought that he had beaten it. Making link to experience over past year, trying to understand this. Anger at staff</u>
	I: Right yeah, Karen	
Death	P1: had just died, round about that time had just died after fighting it for 7 years, so automatically what you do is you start going over what you've heard, you may have heard before that so and so died after a long illness or had been battling cancer for years and I think that myself at the time this is unbelievable, ah thought I'd got rid of this. Now looking back I'd spent the last year trying to figure out what it was and now your telling me I've got cancer again. I was quite angry, not (pause) more inside I never kind of let it out and really I think that I probably should have let it out. I got told I've got to go in the western, the cancer centre and I got told to go across the road which I think is like	Trying to make sense of illness, implies thinking about meaning of own symptoms and emotional processes involved in diagnosis. Shock, disbelief, anger: like bereavement/grief cycle.  Cancer as disease to be fought. Social perceptions of the disease. Shift in life expectancy. Immediate processing of cancer in terms of loss threat – suggest that elicits a coping response, emotional focussed rather than practical. Trying to figure out.  <u>Emotional experience of anger but not displaying this. Second thoughts about consequences of not displaying anger. Going back to treatment, being told where to go.</u>  <u>Pause, reflection as something experienced but not displayed. (not, more inside)</u>  Why not let anger out – afraid of loss of control. What would that mean? In context of now being told what to do? Dependency on others therefore doesn't want to display negative emotion? Regrets over this – why? Belief about impact in self of holding on to negative emotion?
Excessive thinking about death		
Impact of diagnosis		
Shock/ Denial		
Searching for understanding		
Anger		
Suppression of emotions		
		Information on Hodgkin's disease

	Ward 1 at the time ah no sure.	<u>explained one of the symptoms he had experienced but never mentioned because he hadn't made the connection.</u>
	I: the day services, right?	<i>Hesitancy, repetition of my wife picked up</i>
		Things making sense, self reproach perhaps in hindsight about not mentioning a symptom.
Self blame/critical	P1: my wife picked up, my wife picked up a booklet on Hodgkin's disease and one of the symptoms in it was an, an aversion to alcohol. And it was one thing I had never mentioned.	<u>Linking new information on Hodgkin's back to first experience of diagnosis. The experience of drinking alcohol had caused him pain but he hadn't made the connection. Wonders about the role of information giving and checking within the health service, feels like his symptoms were not properly assessed. No one mentioned to him the link between alcohol for instance.</u>
	I: Yeah	
Physical pain	P1: now when I had the cancer the first time round, now if I even had a drink I was in extreme pain, real pain. Right across here and I would have to lie like holding it and it never twigged to me, that that would be anything to do with, I never thought what is this?. If was I being told, and had some sort of box or checklist. And this is like another thing that I would say look <u>you've got to checklist everything</u> , because in one of the tick lists it said, sweats, em, coughing blood or whatever it might be because never, nobody	<i>Emphasises pain, (pain, extreme pain</i> <i>Emphasises; never, nobody ever</i> <i>Hesitation, listing symptoms.</i>  Connecting to experience of previous diagnosis, feeling that medical staff failed to properly assess him perhaps and that if he had been asked about certain symptoms the Hodgkin's would have been picked up earlier. You have got to checklist everything. Other people failed him when he is dependent on them. With his life? Wondering how was he to know? Self recrimination on his part too, should he have guessed? Also blame on others.  One of the first things in the leaflet, does that make it feels obvious? Anger
Searching for explanation		
Lack of knowledge		
Failure of medics		
Anger		

# Appendix 7: Sample of Transcription and Coding

	ever mentioned to me like alcohol, and its one of the first things it said in the Hodgkin's leaflet, an aversion to alcohol.	Talking about pain- how does this link?
		<i>Tails off</i>
	I: yeah	Why does he emphasise pain and hurting again here? It seems out of context to previous sentence. Perhaps emphasising alcohol and his experiences. Perhaps emphasising emotional pain?
Pain	P1: the pain it hurts, so that kinda	
	I: that must have been really frustrating, though	<u>Talks about length of time he had been misdiagnosed, what the impact has been but aware that it's progressing. Confusion and anger and loss of trust with medical staff. Talks about being explicit in talking about this and testing new consultant.</u>
Searching for an explanation	P1: thinking look we've spent a year trying to figure what this is and I don't know how much damage this is doing to me just now. All I know is that the cancer here on the right hand side is getting bigger, em God knows what's going on, so I was kinda angry I would say and I did kinda take it out on ***** a wee bit by saying how can I trust you?	<i>Starts talking about this kind of out of the blue. Using we've - back to collaborative. Pause before talking about the uncertainty of what has been happening. Minimisation of anger perhaps (kinda) and lack of trust (kinda)</i>
Anxiety		
Anger		Thinking comes out of nowhere, has been ruminating on this and his ongoing physical health problems. Fear, uncertainty about the impact of lack of treatment/ wrong treatment. Lack of knowledge yet this is impacting on him. Feels like the disease process is alien to him. Anger at the medical team at the violation of their duty of care: fundamental breach of this relationship inherent in lack of trust?
Loss of trust in medical staff		<u>Loss of trust, feels like this is somehow worse than being treated by a junior dr. No disrespect: does that mean that he should be treated with respect or is this a social formality.</u>
	I: That sounds reasonable	
Loss of trust	P1: a lot of trust ah think, a lot of trust had gone, [REDACTED]	<i>Repetition/ emphasis of : a lot of trust</i>
Failure of medical staff.		Relational aspects of medical treatment, embedded in social context. Violation of relationship on part of medics made worse in part by this being an 'expert'. How can he



## Appendix 7: Sample of Transcription and Coding

	██████ I wasn't dealing with some low sort of junior doctor	have trust in anyone else when the expert let him down? Loss of faith in system he is dependent on. .
		<u>Explaining, emphasising that this was someone with medical knowledge and experience not newly qualified. Frustration that these experts failed him, should have known.</u>
	I: yeah, it wasn't an sho	
Faith in medical staff and their skill violated	P1: aye it wasn't somebody who had just come out of uni or whatever, em and I feel that somebody somewhere round that table should have realised what I had.	Expectations of relationship, patients seek knowledge. Is this what the medics have access to. This is what creates dependency. Not so easy to excuse a mistake because they are experts not learning. Nature of the role held.
	I: I wonder because you mentioned a lot the fact that the uncertainty and them standing on the fence, that you had to go through a lot	<u>Incredulity that no one could diagnose him when it was a disease that he had heard of and possessed knowledge of.</u>
		<i>Emphasises: nobody, nobody</i>
Medical staffs failure to take responsibility	P1: and nobody, nobody seemed prepared and its not as if when I was told what I had it was something unusual. As soon as they said to me you've got Hodgkin's disease ah knew what it was.	Again, sense that medical team as expert should have access to the knowledge made worse perhaps by his awareness of the disease once given his diagnosis. Nobody seemed prepared: does this relate to risk? Is no one prepared to take a risk or responsibility for his diagnosis??
Loss of faith trust		<u>Unknown: wondering what it was going to be.</u>
	I: yeah	Tails off, hesitancy.
Uncertainty	P1: for months we were thinking we're gonna have, some kind of some kind of ....	This appears to reflect the uncertainty of the diagnosis, thinking about it ruminating. We does this refer to him and his family. Illness as a shred social phenomenon?
	I: unknown?	<u>Predicting the worst, felt like it had to be something unusual because no one had given him a</u>

Fear of death

1. because, ah, (sighs ) ah mean a lot of things go through your mind like em, you don't want to be another statistic where folk have fought for years and know what ah mean and never beaten. Ah mean, Ah think at that time ah cant remember who it was ah think it was Gloria Hunniford's daughter

I: Right yeah, Karen

P1: had just died, round about that time had just died after fighting it for 7 years, so automatically what you do is you start going over what you've heard, you may have heard before that so and so died after a long illness or had been battling cancer for years and I think that myself at the time this is unbelievable, ah thought Id got rid of this. (Robert, 33-47)

2. I think when somebody kind of puts it on the line like that to you that kind of frightened me as well. (Robert, 1255-1256)
3. But I know ah mean , I, I know, I know you are going against the clock at that point....., but it was just you know ah have to admit it was a horrible part of it.(Sarah, 92-94)
4. ehm I mean I had just been feeling the pain, but then my mum walked through and of course the clot just hit and I couldn't get my breath or anything. I thought I was having a heart attack or something at that point ehm and of course my mum just walked in at that point and seen the state of me, gasping for breath and what not.

Ehm so they got me hooked up to the machines, got the air onto me and whatnot. I just didnae know what I had, still am like heartburns really bad (both laugh). And then I go up to the ward and \*\*\*\*\* came through to me and says you know we have taken chest x-rays and there is a blood clot sitting on your lung and I was just like, right okay and about 5 minutes after that they left the room and I just had another attack but this time I just couldnae breath at all I was just sort ae climbing. I was actually I don't know why but it must just be something but I was actually climbing up the back of a chair, trying to get breath. Ehm and my mum was like shall I get a doctor and am looking at her like that, I'll be fine in a minute, I'll be fine in a minute. She went no you'll no and came through with about four nurses just came charging through and ehm got me on the bed and sort of got oxygen down me and gave me some valium and that to try and calm me but by that time I thought am a gonner ehm and I thought I cannae do this in front of my mum (laughs) ah don't know what I was thinking. (Sarah, 335-360)

5. I thought well they are no gonnæ, you know, when I first couldnae eat and think you your like it des matter you see this bag with all this food in it that they are drip feeding you and you think you know how am I going no feel hungry and then ah thought , there no gonnæ let me die. I am gonnæ get food in me, you just lie there and you've just got to think well I am no gonnæ starve, they'll no let me die. So that must be able to, to keep me alive so ehm. (Sarah, 1367-1374)
6. well just, that many people die ay these things. I know there's so many different cancer types but how anybody says it doesnae go through their minds ... it's the first thing that does .. there is always somebody dyin .. Kinda bein in there and I soon got to know people and they've died ... it's a hard thing. I mean you know the older you get the percentages are higher for that to happen, its quite hard. (David, 77-81)